

**The relationship of coping and social support to  
distress in couples where one partner has  
Multiple Sclerosis.**

Elaine Carr

D.Clin.Psychol.  
University of Edinburgh  
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## **REFERENCES**

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## **DECLARATION**

**"This thesis has been composed by myself and the work contained herein is my own"**

**Signed** \_\_\_\_\_ **Elaine Carr**

## **ABSTRACT**

Multiple Sclerosis is a chronic and progressive disease with an estimated prevalence of 116 cases per 100,000 adults in England and Wales and 158 cases per 100,000 in Scotland (Swingler, Rothwell, Taylor, & Hall 1994). Although the psychological consequences of MS on the individual are well established, little is known about the psychological impact of this condition on the partner's well being. Researchers have indicated that carers, particularly spouses experience significant levels of stress, when caring for a partner with a chronic illness. While it is commonplace to assess either patient or carer individually in terms of psychiatric morbidity, little research has been conducted into the psychological effects of chronic illness on couples. This was the focus of the present study. Although coping and social support have been found to be important in moderating the impact of stress in both patients and carers at the individual level of analysis, little is known about how these strategies operate in couples facing chronic illness. The present study examines the role of coping and social support and their relationship to distress in 42 couples where one partner has MS. Illness characteristics such as length of diagnosis and level of disability were also examined. Results are discussed in terms of how couples manage the impact of the illness, and what procedures can be put in place to ensure that the needs of both patient and partner-carer are met.

## **INTRODUCTION**

### **1.0.1 General Introduction**

Chronic illnesses have been defined as long term conditions encompassing a course that may be stable, unpredictable or progressive (Lyons, Sullivan, Ritvo & Coyne, 1995). The most common cause of chronic neurological disability among young and middle aged adults in the United Kingdom is Multiple Sclerosis (MS) with an estimated prevalence of 116 and 158 per 100,000 adults for England and Wales, and Scotland respectively (Swingler, Rothwell, Taylor, & Hall, 1994).

The World Health Organisation (WHO, 1980) classification system for the consequences of illness is particularly relevant here. 'Impairment' is defined as any abnormality of physiological or anatomical structure or function (physical changes). 'Disability' refers to the limitations imposed by the disease process; difficulty functioning in everyday activities (such as walking or reading). The degree of 'handicap' or disadvantage experienced in the performance of social roles are influenced by societal values and attitudes toward disability, as well as the individuals attitude toward disability. While the illness is likely to create varying levels of impairment, disability and handicap for the sufferer, there is also likely to be significant effects experienced within the immediate family, particularly the spouse who may have to provide long term care.

There has been a growing body of research which suggests, not surprisingly, that people with chronic illnesses like MS are at considerable risk for emotional disorders (Rao, Huber, & Bornstein, 1992). Research has also found that family members who care for the person can also experience an impact on their emotional well being (Gregory, Disler & Firth, 1996; Knight, Devereux & Godfrey, 1997). While these studies shed light on distress in either the patient or carer, there are few studies that examine the experiences of both members of the couple, and the factors responsible for mediating their distress (Pakenham, 1998).

### **1.1.1. The nature of MS**

Multiple Sclerosis, literally translated as 'many scars' is a chronic, progressive disease. Scarring (often referred to as demyelination) is caused by damage to the myelin a fatty sheath insulating the nerves. One of the identifying features of MS is the existence of sclerotic plaques or lesions mainly in the white matter of the brain and spinal cord (Robinson, 1988). As a result of demyelination, a wide variety of symptoms can occur such as loss of function or feeling in limbs, bowel or bladder problems, sexual dysfunction, debilitating fatigue, blindness due to optic neuritis, loss of balance, pain, loss of cognitive functioning, and emotional changes (Goodkin, 1992). The presence of these symptoms can vary enormously between individuals, and over time.

Typically MS is characterised by periods of exacerbation (periods where symptoms are present) and remissions (abating of symptoms). This type of course is most common in the early stages of the disease. However, longer duration of MS is generally associated with the presence of greater symptomatology as the disease process progresses. It is possible to identify different patterns of disease progression in MS as indicated below (Bates, 1993).

### **1.1.2 Patterns of MS**

- Relapsing-remitting: recurrent attacks of neurological dysfunction (exacerbations) that occur irregularly and are followed by periods of complete or partial recovery (remissions). When recovery following relapse is incomplete, disability will gradually increase in a step-wise progression. This category of relapsing remitting MS includes people with varying levels of impairment and disability. The majority of people with MS have this form of the disease, but most of them eventually develop a secondary progressive course (Bates, 1993).
- Primary progressive (or chronic progressive): this course entails continual decline from the first attack without exacerbation or remissions (Bates, 1993).

- Secondary progressive: with time, relapsing-remitting MS usually develops into a gradual disability, and a secondary progressive course is often described. Although its pattern varies among individuals, most commonly there is a slow deterioration of functioning (Bates, 1993).
- Benign: there may be a long period between the onset of the disease and the manifestation of disability. While some cases may remain benign throughout the life span, others may convert to a secondary progressive course (Bates, 1993).

Diagnosis of MS is difficult, and relies on evidence of multiple central nervous system lesions over time, and the exclusion of other causes (Vanderplate, 1984). Computerised tomography (CT) scans have been used as an aid to diagnosis and they have indicated enlarged ventricles resulting from cerebral atrophy in approximately 40 per cent of MS patients (Rao, Glatt, Hammeke, McQuillen, Khatri, Rhodes & Pollard, 1985). However, CT scans have often revealed that there may be large areas of lesions with no symptoms evident, and on the other hand a few lesions can produce significant symptomatology (Rao *et al.* 1985). Thus it can be difficult to provide a definite diagnosis of MS, and patients are often given the diagnosis of 'probable' MS (Benz, 1996).

The aetiology of MS is unknown, although viral, trauma, and genetic influences have been indicated, and it has been proposed that the disease results from a complex interaction of the immune system, genetic factors, and early exposure to unspecified environmental agents (McKhann, 1982; McDonald & Silberberg, 1986). It is important to note that although progressive, MS is not fatal, and many individuals can live a normal lifespan.

### **1.1.3 Characteristics of MS patients**

This is a disease with an onset in young adulthood and generally occurs in midlife in the ages of 20-50 (Rolak, 1992). The median age of onset is 33 (Devins & Seland, 1987) and women appear twice as likely to be affected as men (Mohr & Goodkin, 1999). It appears that MS is more prevalent in temperate regions, than in the tropics (Antonak & Livneh, 1995) and in the British Isles it is estimated that 80 per 100,000 suffer from MS, with this figure doubling in north-east Scotland. Particularly striking are the dramatic increases in the Orkney and the Shetland isles, 258 and 152 per 100,000 respectively (Poskanzer, Prenney, Sheridan, & Yonkondy, 1980).

The problems associated with MS can be classified as physical, cognitive, social, and emotional and will be discussed below:

#### **(a) Physical problems**

As demyelination can occur anywhere in the CNS, the manifestation of MS can vary greatly between individuals, and a wide range of physical problems can present. Typical manifestations are increased reflexes, spasticity, weakness, sensory loss, visual impairment, bladder and bowel dysfunction, pain, and fatigue. Muscle spasticity is one of the major causes of disability and one of the most common clinical features of MS (Ko Ko, 1999). It can lead to pressure sores, difficulty in sexual activity, painful spasms and contraction of limbs. As the cause of MS is still unknown, treatment is aimed at specific symptom treatment. This may be alleviated through a combination of drug treatments (in the case of bladder control), or alternatively, patients may receive physiotherapy to help reduce spasticity (Ko Ko, 1999). Understandably, these symptoms can lead to increasing disability and gradual reductions in mobility.

#### **(b) Cognitive problems**

Cognitive deficits have been reported to occur in up to 50 per cent of MS patients (Peyser, Edwards, Poser & Filskov, 1989; Rao, Leo, Ellington, Nauertz, Bernardin, &

Unverzagt, 1991). Of this, about 40 per cent will have mild dysfunction, and about 10 per cent will have moderate to severe impairments (Rao *et al.* 1991). A 'subcortical dementia' has been used to describe the typical pattern of deficits which is characterised by apathy, depression, forgetfulness and slowing of mental processes, problems in manipulating acquired knowledge and personality change (Gilchrist & Creed, 1994).

### **(c) Social problems**

Chronic illnesses like MS can present considerable challenges to the sufferer. Depending on the nature of the impairment, and their previous social and occupational environment, individuals may experience considerable adjustments in their social and occupational functioning. For example, individuals whose occupation relied on good physical functioning and whose social activities revolved around sports will undoubtedly experience the greatest impact. Many individuals with chronic illnesses report that social contacts decrease considerably since the onset of the illness (Gilchrist & Creed, 1994). A research study found that approximately 10 years after diagnosis, between 50 and 80 per cent of individuals with MS had retired from work (Rao *et al.* 1991).

### **(d) Emotional problems**

As noted above, chronic illnesses like MS can have substantial negative consequences on the sufferer resulting in increased risk for psychological distress. The loss of function, and in some cases the consequent loss of employment as well as important social roles may well be a contributing factor. The presence of emotional disorders in chronic illnesses like MS has long been documented (Whitham, 1994).

Depression has been the most commonly studied psychiatric concomitant of MS, and estimates of the prevalence of depression have varied considerably, with one of the earliest studies reporting it to be as low as 6 per cent (Kahana, Leibowitz, & Alter, 1971), with later studies estimating between 27 and 54 per cent (Minden & Schiffer,



1990). An increased risk of suicide has also been noted (Stenager, Stenager, Koch-Henriksen, Bronnum-Hansen, Hyllested & Bille-Brahe, 1992).

Conflicting findings with regard to reports of depression may be due to considerable methodological problems in the early studies. Many had small numbers, no control group, varying methods of assessing depression and, most importantly did not consider illness related variables (Minden & Schiffer, 1990). Not taking account of specific illness related factors such as length of diagnosis, and severity of disability (Vanderplate, 1984), may give the impression that depression is common in all individuals with MS. However, while it may appear reasonable to assume that those with a greater degree of impairment and disability may be more distressed, the evidence is conflicting. Some studies have found a relationship between a greater degree of physical disability and a more severe disorder (McIvor, Riklan & Reznikoff, 1984; Zeldow & Pavlou, 1984), and others have found no relationship (Dalos, Rabins, Brooks & O'Donnel, 1983). Similarly, longer duration of illness has been related to a better psychological outcome in some studies (Maybury & Brewin, 1984; Rudick, Miller; Clough, Gragg & Farmer, 1992), and again others have found no relationship between duration of MS and depression (Minden & Schiffer, 1990; Barnwell & Kavanagh, 1997). More recently, the course of MS has been taken into consideration; Vleugels, Pfenning, Pouwer, Cohen, Ketelaer, Polman, Lankhorst & Van der Ploeg (1998) found MS patients with primary progressive MS, had better psychological functioning compared to those with a secondary progressive course. This finding was accounted for in terms of the former adjusting better due to the constant presence of symptoms, while the latter had to contend with variations in symptom presentation. Essentially, this study suggests that the unpredictability of symptoms is a more significant predictor of distress in MS.

The results of studies that have examined illness related variables and depression are conflicting perhaps suggesting a complex relationship. It is possible that studies where no association was found between severity of disability and distress is due to

the fact that many of the more severely disabled patients have had MS for a number of years, and have adapted to their situation. Furthermore, it is possible that the younger are less impaired, but more distressed as they have not come to terms with their condition. A study by Devins, Styra, O'Connor, Gray, Seland, Klein & Shapiro (1996) found that age was a significant predictor of psychological well being in their sample of MS patients. More specifically, as age and the amount of illness related symptoms increased, psychological distress decreased. Devins *et al.* (1996) suggest that two possibilities exist with regard to this finding. One, as noted above, older patients are less distressed as they have adapted to their condition. Alternatively, greater distress in younger patients may be due to the premature occurrence of a disabling condition when they have not had the opportunity to achieve their goals in life. Few studies have examined the impact of gender on distress. It is possible that the higher levels of depression reported in some studies may be a result of a greater number of women being affected by MS, and more likely to report symptoms of distress (Nolen Hoeksema, 1987). However, one study found that gender was not a significant determinant of distress (Zeldow & Pavlou, 1984).

Cerebral impairment has also been implicated as a possible factor of depression in MS. Dalos, *et al.* (1983) found that MS patients with evidence of cerebral impairment were more depressed than MS patients with spinal cord involvement. However, Rao *et al.* (1991) found no difference between MS patients with cognitive impairment and those without on the Zung depression scale or the State Trait anxiety inventory. Overall, the research examining the contribution of cerebral impairment to the presentation of depression is inconclusive.

Research has suggested that compared to controls and other patient groups, depressive disturbances are more common in individuals with MS than the general population (Minden, Orav, & Reich, 1987), patients with various neurological illnesses (Whitlock & Siskind, 1980), patients with non-central nervous system disabling conditions such as spinal cord injury (Dalos, *et al.* 1983) and amyotrophic lateral sclerosis (Schiffer &

Babigan, 1984). At present it is not possible to state whether this is due to factors such as greater levels of disability in the samples studied, the impact of cerebral impairment or problems concerned with the measurement of depression in individuals with MS.

When assessing distress in MS it is important to be aware of the confounding of symptoms of MS with depression. Symptoms such as chronic fatigue, problems of concentration and memory may be attributable to MS, thus giving the appearance of depression, without it being necessarily present. It is unclear whether or not this has been taken into consideration in past studies that have relied on subjective interviews, but in more recent studies that use standardised questionnaires, results should be treated with caution if there is too much emphasis on the physical symptoms of depression.

#### **1.1.4 Summary**

Although the discussion above suggests that people with MS have more elevated rates of distress when compared to other patient groups and the general population, (Minden *et al.* 1987; Whitlock & Siskind, 1980), it is not clear what accounts for distress in MS. As with any other chronic illness, it is likely that some of the distress experienced is associated with the corresponding losses of function and social role, although there is conflicting research that suggests there may be a degree of cerebral involvement in association with depression. Whitham (1994) suggests that the frequency of psychiatric disorders in MS may be multi-factorial and may be due to either one or a combination of the factors below:

1. Coincidental association of diseases common in young adults
2. Psychological reactions to a uniquely unpredictable and disabling disease
3. Organic factors (alterations in nerve conduction or neurotransmitter metabolism as a consequence of inflammation or demyelination)
4. Shared viral, autoimmune or genetic factors.

Therefore, at present it is not possible to attribute the cause of depression in MS to any one factor, but it is likely that a combination of factors may be responsible.

The present study aims to examine the level of distress in MS patients using two measures of distress; the Hospital anxiety and depression scale (HAD) Zigmond & Snaith (1983) and the General Health Questionnaire (GHQ) Goldberg & Hillier (1979). The former was adopted due to its lack of physically confounding items, and the latter to allow comparisons with previous studies. It also aims to examine the impact of various demographic variables such as gender and age, as well as illness related variables such as level of disability, length of diagnosis and their association with the presence of distress.

### **1.2.0 Impact of chronic illness on the partner**

Undoubtedly, understanding the impact of the illness on the individual with chronic illness is essential as it can have major repercussions emotionally, socially and economically, not just on the individual but in the environment in which they exist. Individuals with chronic illnesses exist within the context of families and close social relationships, and it is perhaps inevitable the illness will take its toll (Lyons, 1991; Morgan, Patrick & Charlton, 1984). Partners and other family members (parents and children) may experience various problems due to the illness, including taking over some of the responsibilities of the patient, in addition to providing care and support for them. Their social life may be curtailed as the patient's disability prevents them from engaging in their usual activity, as well as the distressing impact of witnessing the patient's pain and suffering.

The impact of chronic illness on the partner has been assessed from different perspectives. One focus has been the impact of chronic illness on the marital relationship (Flor, Turk & Sholz, 1987). Although some research has examined the effects of illness on the partner where caregiving is not required, this is uncommon (Northouse, Dorris & Charron-Moore, 1995). In many cases it is difficult to extricate the effects of the illness from the effects of caregiving as the two are interwoven. This is because caring is embedded within normal relationships, and there is a continuum from caring about someone to providing care. More commonly however, the focus has been on the effects of caring for a disabled partner (Zarit, Todd & Zarit, 1986).

Despite the demands that MS places, there is little evidence that examines the impact on the partner's social and emotional wellbeing (O' Brien, 1993; Pakenham, 1998). In contrast, however, an abundance of research exists with regard to the effects of caregiving in other ongoing deteriorating conditions, such as dementia (Gilhooly, Sweeting, Whittick, & McKee, 1994; Zarit & Edwards, 1996).

### **1.2.1 Caregiving**

The provision of help or support to a disabled person is often referred to as 'caregiving' in the research literature; this term was originally used in association with carers of older adults, particularly with Alzheimer's disease (Zarit, Reever & Bach- Peterson, 1980). Increasingly, caregiving has been examined in relation to other groups such as cancer (Clipp & George, 1993) and Acquired Immune Deficiency Syndrome (AIDS) (Folkman, Chesney, Cooke, Boccellari & Collette, 1994).

Caregiving has been defined in different ways; some studies have stated that it is the number of hours spent helping in a practical sense (Travers, 1996). Others have defined it as the activities and experiences involved in providing help and assistance to someone who is unable to provide for themselves (Pearlin, Mullan, Semple & Skaff, 1990) suggesting both the emotional and practical side of providing care. Similarly, Zarit & Edwards (1996) suggest that caregiving is an interaction in which one person is helping another on a regular basis with tasks of independent living. In many cases, it is difficult to know where caregiving actually starts and ends, as it is embedded in normal relationships, and in many cases the role may develop gradually over a period of years (Tennestdt, 1999). Although perhaps an insidious process, caregiving represents a change in relationship roles, where after some time, one person is dependent on another for help.

### **1.2.2 Impact of caregiving**

An extensive research literature exists that has established that caregiving may be associated with increased rates of physical and psychiatric morbidity (Schultz, Visintainer & Williamson, 1990). For example Morris, Morris & Britton (1988) found that caring for a disabled relative was associated with higher incidence of emotional disorder, accompanied by loss of morale, lowered affect and increased stress in their study of caregivers of dementia sufferers. Others have noted that caring for a relative with Alzheimer's disease has been associated with symptoms of distress such as anger, frustration, and anxiety (Schultz, Tompkins & Rau, 1988; Gilhooly *et*

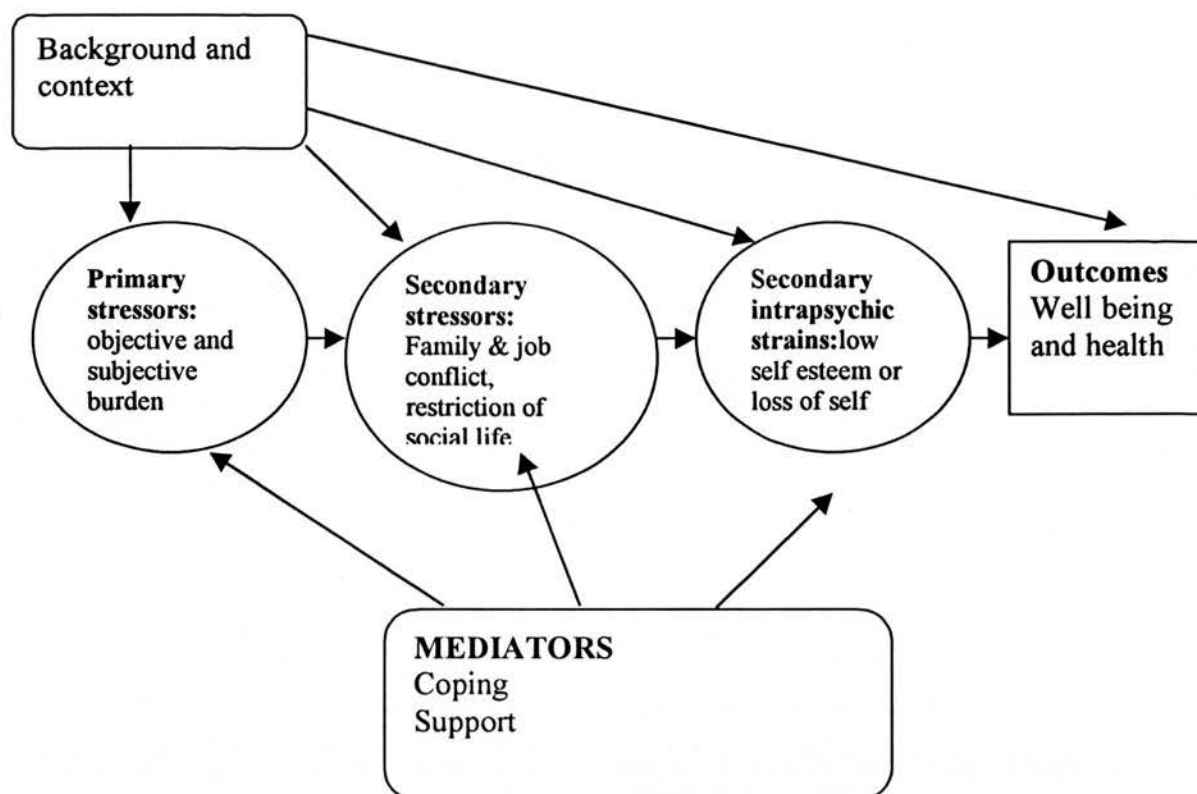
*al.* 1994; Tenenstedt, 1999). In addition, there is evidence that greater levels of psychotropic medications are taken by caregivers as opposed to the normal population (O'Brien, Wineman & Nealon, 1995). Although symptoms of psychological distress are widely reported, prevalence rates have varied from 20 to 80 per cent across studies (Thompson, Coon, Rivera, Powers & Zeiss, 1998), with some studies finding caregivers to be in good mental health or only mildly affected (Gilhooly, 1984). Variability in reports of distress and depression may be due to a number of factors, not least the type of assessment measure used and the sampling techniques used by many of the earlier studies.

The extra demands placed on families caring for physically or intellectually impaired individuals has been referred to as 'burden', (Zarit, *et al.* 1980) or more recently 'strain' in the research literature. George & Gwyther (1986) defined burden as 'the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults'. Grad & Sainsbury (1965) conceptualised burden as 'subjective' and 'objective'. Subjective burden refers to the emotional response to caring, the caregiver's perception of strain and the distress associated with this, while objective burden refers to the practical consequences of the disability on their lives; the extent of disruption to their life.

### **1.2.3. Model of caregiver stress**

Perhaps one of the most influential and widely used models of caregiver stress is that espoused by Pearlin, Mullan, Semple & Skaff (1990). Pearlin *et al.* (1990) developed a theoretical framework in which to understand caregiver stress or strain. This framework took into account concepts such as objective and subjective burden, primary and secondary role stress, as well as recognising the individual nature of caregiving burden by including a variable known as 'intrapsychic strain' (Figure 1).





**Figure 1: Pearlin *et al.* (1990) model of caregiver stress.**

This model has been used to understand and organise findings from the research literature. The primary stressors can be conceptualised as the subjective and objective burden associated with caregiving (as described above). The secondary stressors refer to the effect that the primary stressors have on caregiver's roles, the impact on other aspects of their life such as their family and occupational commitments. Secondary intrapsychic strains refer to the impact that role strains can have on caregivers self esteem. Coping and social support are the mediators by which the effects of caregiving can be mediated. The present study is concerned with how distress (both spousal caregiver and care recipient) can be mediated and is concerned with the hypothesised mediators of coping and social support, which will be discussed at length later.



Although the early research may have given the impression that caregiving was universally stressful, there has been much criticism of these findings (Tennestdt, 1999). In particular, many studies used selective samples of caregivers that had sought help from various services, and self help groups (Barer & Johnson, 1990; Tennestdt, 1999). It is possible that help seeking caregivers are likely to have the greatest need and to report more negative consequences (MaloneBeach & Zarit, 1991). In addition, most of the research has been conducted on caregivers of dementia sufferers, and therefore cannot be generalised to other groups of carers. It has been argued that caring for someone with dementia is more stressful than caring for someone with a physical disability due to the physical and cognitive impairment present in this group (Birkel, 1987). Whittick (1988) notes that carers of dementia may be more stressed due to the awareness that deterioration in the patient is inevitable.

Criticism has also been directed at the one-sided approach of many caregiving studies to focus on stress and distress, and cue participants to focus on the most negative aspect of their experiences, without asking about the more positive aspects of their experiences. Additionally the widespread use of 'burden' scales has made comparisons with normal populations difficult (George & Gwyther 1986), and the assessment of burden as opposed to distress makes it difficult to establish and argue for treatment for caregivers. For these reasons, more recent research has moved away from assessing burden and now tends to focus on assessment of anxiety or depression. The General Health Questionnaire (GHQ; Goldberg, 1979) has been one the most widely used measure. Using this measure, a third of Whittick's (1988) dementia caregivers achieved scores indicative of clinical caseness.

Other criticisms that have been directed at the early research is the failure to account for factors such as gender age, illness related variables and relationship of carer to care recipient (whether they are partner or other family member). These predictors of caregiver distress will now be discussed.

#### **1.2.4 Factors associated with distress in caregivers**

##### **a) Characteristics of the care recipient: illness related variables**

While it may be assumed that caregivers of the severely disabled would feel significantly strained as characterised by heightened levels of psychological distress, this is not a consistent finding in the literature. The degree of disability in the care recipient has not been considered a significant factor in caregiver outcomes in dementia (Tennestadt, Cafferata & Sullivan, 1992). In contrast, subjective burden or the caregiver's appraisal of the situation appears to be a more powerful predictor of psychological distress in caregivers of individuals with a mental illness, (Coyne, Kessler, Tal, Turnbull, Wortman & Greden, 1987) and dementia (Zarit *et al.*, 1986).

##### **b) Characteristics of the caregiver**

Many of the early studies in caregiving were criticised for not taking account of important caregiver characteristics such as gender, age and relationship of caregiver to care receiver. Women for example are more likely to be caregivers, and it is possible that the heightened levels of distress reflect gender effects of women being more likely to report distress than men (Gilhooly, 1984; Nolen-Hoeksema, 1987). When gender and age of caregiver are taken into consideration, research indicates that female caregivers report greater levels of subjective burden (Fitting, Rabins, Lucas & Eastham 1986; Pruchno & Resch 1989) and depression (Cantor, 1983). Furthermore, research indicates that younger spouses report more subjective burden and psychological distress than older spouses (Fitting *et al.* 1986). However, there is evidence to suggest that this may not be a function of age, but more likely to be due to older caregivers having adapted to the demands of caregiving, or alternatively because chronic illness is more expected in older age (Tennestadt, 1999). There is some evidence to suggest that spousal caregivers experience more stress or strain and experience higher rates of psychiatric symptoms than other groups of caregivers (George & Gwyther, 1986).

### **1.2.5 Impact of MS on partners**

As noted above it is not just the patient who is affected by the illness, partners and families may also experience significant emotional and social impact. Arguably, the impact may be greater for partners of people with MS than for other chronic illnesses as MS often occurs in young adults early in their marriages, and careers and they are more likely to have young children (Murray, 1995). In an illness with a higher incidence of females, the male partner is most likely to be the main source of support. Unfortunately, little is known about the effects of MS on the partner, particularly male partners and the research that has been conducted has focused exclusively on the effects on the marital relationship or caregiving. Although many partners are caregivers, this is not always the case, and we know little about effects on the partners who are not caregivers. There are many reasons why they may not be caregivers; not least the demands of employment in younger partners or a poor relationship with their spouse.

### **1.2.6 Caregiving in MS**

The partner is most often identified as the carer for people with MS. Aronson, Cleghorn & Goldenberg (1996) reported that 65 per cent of their sample of MS patients identified their spouse as their primary caregiver. Evidence regarding the effects of caregiving in MS are limited (Gregory *et al.*, 1996; Pakenham, 1998).

Mounting evidence suggests that MS caregivers face multiple physical and psychosocial adaptive demands (Aronson *et al.* 1996; Cockerill & Warren, 1990). In their study of predominately spousal caregivers, Dewis & Niskala (1992) found caregiving affected well being, and many of their sample reported nervousness, insomnia and other mood problems. Furthermore, over a third reported worsening of long-standing health problems, with 18 per cent noting the development of new health problems. However, this study had a predominance of female spouse caregivers and it may be that this latter finding may be an artifact of gender. Knight *et al.* (1997) found a range of negative effects in his study of MS spousal caregivers similar to those

reported by other groups of caregivers with degenerative neurological diseases. He noted that caregivers reported considerable time burden, particularly time available for the rest of the family, as well as being concerned about the future. Interestingly, this study presented positive effects in the qualitative analysis; caregivers reported that living with someone with MS had made them more caring towards other people.

Interestingly, O'Brien, Wineman & Nealon (1995) found no evidence of psychological distress in their sample of MS caregivers. Caregivers rated quality of life as good and scores on a measure of general health (GHQ 28) were in the normal range. Few studies have examined whether there are positive benefits associated with caregiving or MS caregiving. The current study aims to investigate this by asking both patients and caregivers to report if there are any positive effects experienced both as a sufferer of MS, and as a partner carer.

#### **1.2.7 Factors associated with distress in MS caregiving**

##### **a) Length of diagnosis and severity of disability**

Unlike other forms of physical disability, the range of disability present in MS sufferers can be extremely diverse. Predictably though, those having symptoms of MS for a longer period are more severely disabled (Sato, Ricks & Watkins, 1996; Winslow & O'Brien, 1992). Few MS caregiving studies have examined illness factors such as years diagnosed and impact of disability on caregiver outcomes. However, O'Brien (1993) found that as care recipient dependency increases, caregivers health promoting behaviours (looking after ones health, physical exercise) decrease. Although this study did not directly assess levels of anxiety or depression in caregivers, it nevertheless provides evidence that greater degrees of physical disability in care receivers compromised caregivers time caring for themselves. Contrary to this, Dewis & Niskala (1992) did not find a relationship between the reported health status of the caregiver and the level of physical disability in the patient. Similarly, O'Brien *et. al.*, (1995) found no evidence to support the notion that greater disability in the patient is

associated with higher level of distress in the patient. Interestingly, in their analysis, subjective burden was a stronger predictor of caregiver's general health (as assessed by the GHQ 28) than objective burden or degree of disability in the care recipient (O'Brien, *et. al.* 1995). The present study aims to examine both the influence of disability and years diagnosed on partner's well being.

#### **b) Gender and age**

As noted above, with a high proportion of females afflicted with MS, their male partners are likely to be primary caregivers (O'Brien, 1993). These caregivers are likely to face different demands to those of caregivers of dementia patients; they are more likely to be younger and be in full time employment and to have dependent children still living at home. Juggling different roles may cause great stress for the young to middle aged male, particularly if in the past there was a gender division of labour.

Knight *et al.* (1997) assessed burden in a group of MS spousal caregivers, and although significant differences were not found between male and female MS caregivers, there was a trend toward women having higher overall burden scores. Investigating this further he found a significant difference only in physical burden; women reporting greater levels of tiredness and sleep problems. In addition, this study did not find any differences between younger and older caregivers in terms of burden. However, the sample was small, and there were significantly fewer spousal caregivers in the younger group, compared to the older group. This appears to be the only study to examine the effects of gender and age in MS spousal caregivers. The present study aims to further examine the influence of gender and age in MS spousal caregivers.

### 1.2.8 Effects of partner's psychological distress

From the discussion above, it appears that both the patient and the caregiver may be at considerable risk for emotional disorders. The discussion examined patients and caregivers individually, which is in line with the majority of research conducted. Few studies in the chronic illness field have examined psychological distress in both the patient and the carer and have assessed only one member of the couple (Lyons, *et al.* 1995). Northouse *et al.* (1995) examined couples where the wife had recurrent breast cancer, and found an association between partners scores on measures of psychological adjustment. More specifically, wives who reported higher levels of emotional distress were married to husbands who also reported higher levels of distress. Furthermore, although distress in husbands was a significant predictor of wife's emotional distress, wife's distress was not predictive of husband's adjustment. This may be suggestive of gender differences in how distress in one member effects the other, with females more likely to be affected by their husband's distress. Similarly, Soskolne & Kaplan De-Nour (1989) found a strong association between distress in dialysis patients and their partners. More recently, Walsh, Blanchard, Kremer & Blanchard (1999) found that distress in patients with rheumatoid arthritis was associated with distress in partners. However, contrary to this, Manne & Zautra (1990) found no association between distress in patients with rheumatoid arthritis and their spouses.

Research that has been conducted where one member of a couple is depressed would suggest the presence of depression in one is linked to a higher level of distress in the other (Coyne & Anderson, 1989). For example, Kahn, Coyne & Margolin (1985) found that spouses in couples with a depressed member withdrew more frequently and used more aggressive coping strategies, and responded to stress with higher levels of negative tension. Similarly, Bolger, DeLongis, Kessler & Schilling (1989) found links between the work stresses of one spouse and home stress of both members of the dyad, and has noted the process of stress 'contagion', where one member's distress can affect the other.



In a study which assessed the distress of patients with MS and their caregivers, Pakenham (1998) found a significant association between patients and carers on measures of depression, interpersonal-sensitivity and hostility, suggesting that distress in one is linked to the other. However, in this study the carers were not all partners or spouses, but comprised of friends and other family members.

Pakenham (1998) also examined the differences between partners distress, and found that MS patients were significantly more distressed than partners on a variety of distress measures. Similarly, findings from a study, which examined patients with rheumatoid arthritis and their partners, indicated that patients were more distressed than partners (Walsh *et al.* 1999). The present study aims to further investigate the similarities and differences with regard to distress in couples where one member has MS.

#### **1.2.9 Impact of MS on relationships**

As noted above, progressive disability associated with MS can lead to increasing dependence on the spouse, perhaps inevitably placing a strain on the relationship. The rate of divorce is twice as likely in MS than the general population (Brooks & Matson, 1982), suggesting a level of marital difficulty similar to that found in couple's where one has acquired a physical disability (Renne, 1971; Hafstrom & Schram, 1984). Dupont (1996) found between a quarter and a third of patients with MS were mildly unsatisfied with their relationship, and male patients were more dissatisfied. The results of a study by Woollett & Edelmann (1988) indicated that both the patient with MS and their partner had a good level of marital satisfaction; although individuals with MS were more satisfied with their relationship than their partners. Similarly, McCabe, McDonald, Deeks, Vowels & Cobain (1996) found that participants perceived no change in their relationships since being diagnosed with MS. However, communication between partners was often low, characterised by a reluctance to discuss problems with their partner. Although this study highlighted interesting findings with regard to the patient, data were not collected from the partner, and it

would have been interesting to assess their perspective with regard to changes in their relationship. Caution is required when interpreting these findings these studies assessed couples had been married for a long duration, and had been diagnosed for some time.



### **1.3.0 Mediators of distress**

The early research in the chronic illness field focused on establishing the presence of depression and consequently viewed individuals with MS within traditional psychiatric constructs (Vanderplate, 1984). This approach has been criticised for its emphasis on psychopathology, and its failure to identify factors that contribute to a more favourable adjustment.

Increasingly research has been attempting to de-emphasise the perception that individuals with chronic illnesses like MS are generally emotionally distressed. Vanderplate (1984) for example, posits that the majority of individuals with MS are relatively 'normal persons' attempting to cope with the stress and unique psychosocial issues the disease presents.

Interest in the factors responsible for mediating stress arose from the observation that many individuals in particularly aversive situations (such as patients with chronic illness) demonstrate remarkable resilience despite considerable disability (Wineman, 1990). Illness related factors such as severity of disability or time since diagnosis have been inconsistent in predicting psychological adjustment in either individuals with chronic illness or their partners. Increasingly, research has used models of stress mediation to understand variations in psychological adjustment in chronic illnesses, and those caring for them. The role of two hypothesised mediators; coping and social support has been highlighted.

### **1.3.1. The concept of coping**

The term 'coping' is used ubiquitously; in common usage it is often used to refer to a person's attempts to manage particular stresses or strains. In general, people tend to 'cope' without realising what they are doing to 'cope'. Interest in what people do when coping with stress has proliferated over the past thirty years, and coping behaviour has been recognised as one of the most important factors that moderate between stress and strain (Billings & Moos, 1981; Endler & Parker, 1990; Lazarus & Folkman, 1984).

Different theoretical standpoints have been proposed to account for how individuals cope, and two very different models have gained prominence. The most widely used is the process model (Lazarus & Folkman, 1984), while the earliest and perhaps less commonly used models are trait based (Valliant, 1977).

### **1.3.2. Process model**

The concept of coping has been greatly influenced by the work of Lazarus and his colleagues (Lazarus & Folkman, 1984; Gruen, Folkman & Lazarus, 1988; Lazarus, 1993; Folkman, 1997). This model of coping focuses on the variable, changing and situation characteristics of the stress and coping process. Coping is defined as the: 'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus & Folkman 1984, p.114)

Lazarus & Folkman (1984) postulated that coping continually changes due to an individual's appraisal of the stress in a situation. How an individual copes with an event depends on their perception of whether anything can be done to alter the situation. If it is appraised that something can be done, 'problem focused coping' predominates; resulting in efforts directed at changing the stress of the situation. On the other hand, if appraisal suggests that nothing can be done 'emotion focused coping' prevails; resulting in strategies aimed at regulating distress, either through direct

management of the distress (i.e. avoiding it) or attempting to alter one's perception of the situation. The classification of coping into problem and emotion focused has been widely used in the research literature.

Although appraisal is one of the key concepts in this theory, Lazarus & Folkman (1984) also recognised the importance of the environment in which individuals are attempting to cope. They note that when there is nothing constructive people can do to overcome the stress, some forms of emotion focused coping may be adaptive; the use of denial in the early stages of a stressful experience (Lazarus & Folkman, 1984).

### **1.3.3 Trait model**

Carver and associates have proposed a variant of the trait approach to coping. (Carver, Scheier & Weintraub, 1989; Carver & Scheier, 1994). While not denying that coping can change from situation to situation, Carver *et al* (1989) postulates that people develop habitual ways of dealing with stress and that these habits or 'styles' can influence their reactions to new situations (Carver *et al*, 1989, Carver & Scheier, 1994). They propose that style of coping may exert a constant influence; if active coping is generally utilised by a person, when a new situation arises it is likely that it will again be employed. Additionally, Carver *et al* (1989) note that a person's coping style may influence situational coping at one phase of a transaction but not at others.

Carver & Scheier (1994) tested their theory with university students coping with exam stress. They assessed students on how they typically cope with stressful situations (dispositional coping). Later, they requested students to assess how they coped with specific phases of the exam stress on three separate occasions. An association was found between students stable coping (specifically denial, use of social support and alcohol) and exam stress (Carver & Scheier, 1994). On the basis of this they tentatively concluded, that how individuals generally cope may play a role in how they cope in specific situations. Terry (1994) added support to this and found that how

participants coped in one situation was one of the strongest predictors of how they coped in a second different situation.

Related to coping, is the concept of optimism and pessimism. The use of optimism has been related to better psychological outcomes than pessimism (Scheier & Carver, 1992). According to Scheier & Carver (1985) better adjustment in optimists is due to the fact that they often attempt to change stressful situations with problem solving (a problem focused coping strategy). Furthermore, one longitudinal study found that pessimism was linked to poorer psychological and physical adjustment 25 years later (Peterson, Seligman & Valliant, 1988).

Although these findings are interesting, few studies exist that have examined the relationship between situational and dispositional coping, and psychological distress, and more research is required to assess this further before any conclusions are drawn.

Whatever theoretical model espoused, research has consistently indicated that problem focused coping is related to a better psychological outcome (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986), whereas avoiding and distancing (forms of emotion focused coping) are related to heightened levels of distress (Folkman *et al.* 1986; Revenson, 1994; Vitaliano, Maiuro, Russo, Katon, DeWolfe & Hall, 1990). However, despite these general findings, not all research has found significant associations between various types of coping and psychological well being. Although emotion focused coping has been more consistently associated with negative outcomes, the relationship between the use of problem focused coping, and emotional well-being is inconsistent (Keefe, Caldwell, Queen, Gil, Martinez, Crission, Ogden & Nunley, 1987). Bomardier, D'Amico & Jordan (1990), for example found no relationship between problem focused coping and adjustment in illnesses in his study of individuals with a variety of chronic illnesses.

It is possible that the links between coping and psychological outcome are inconsistent due to variations in the nature of the stressor. As noted above, Lazarus & Folkman (1984) suggest that the nature of the stressor is essential. In situations which are not amenable to change, rational problem focused coping may be counterproductive or unlikely to result in change or amelioration of the stress, and perhaps more likely to result in distress. In these situations, emotion focused coping may predominate and therefore be more appropriate (Lazarus & Folkman, 1984).

#### **1.3.4 Critique of coping theory and assessment**

Major criticisms have been directed at coping theories, and the way that coping has been measured. Criticism directed at one approach or another comes essentially from those who favour either a state (Folkman & Lazarus, 1984) or trait approach to coping (Carver *et al*, 1989, Carver & Scheier, 1994). The debate between the two perspectives is ongoing, and the possibility exists that they are complementary rather than conflicting.

Criticism has also been aimed at the way coping is measured. Lazarus & Folkman's 'Ways of Coping Checklist' (WCC, 1984) is the prototypical measure used or adapted by most investigators. This type of questionnaire contains a list of coping strategies which asks respondents to rate what extent they used specific coping strategies in a recent stressful situation (process approach) or to what extent they used them in general (dispositional approach). It has been noted that respondents may tend to respond in a socially desirable manner, in terms of how they would have liked to cope rather than how they coped in reality. The measures have been criticised as too general, and as such have difficulty capturing how individuals cope in highly specific encounters such as coping with a chronic illness (Pakenham, 1998). Although the WCC is the most commonly used measure, many researchers have adapted the wording and specified the stressor, making comparison between studies difficult.

#### **1.4.0 Coping with a chronic illness**

Chronic illnesses pose considerable challenges to both patient and partner. Learning to cope with continuous physical symptoms and the consequential changes in other domains of life will test the resources of most individuals. The stress-coping model of Lazarus & Folkman (1984) is one of the dominant paradigms used in the chronic illness field. This model has provided very fertile ground for those attempting to discover what factors mediate individuals psychological adjustment, when they are afflicted with an illness or disease or when they are caring for someone with a chronic disease.

Studies with chronically ill populations have confirmed findings from general stress and coping research; exercising some form of control over the disease (problem focused coping) is related to positive adaptation (Pollock, Christian & Sands, 1990; Revenson & Felton, 1989). Use of emotion focused coping strategies have been related to high levels of distress (Revenson & Felton, 1989), particularly, avoidance and wishful thinking (Mattlin, Wethington & Kessler, 1990; White, Richter & Fry, 1992).

It is important to note that different approaches have been taken to studying coping in chronic illness. Some researchers have been interested in how people cope generally with the stress of the illness, others have been interested in how people cope specifically with regard to one aspect of their illness, such as coping with pain, or coping with the loss of social networks (Blalock, DeVellis, & Giorgiono, 1995). Blalock *et al.* (1995) assessed coping with regard to the specific problems associated with rheumatoid arthritis, and found no evidence that patients changed their coping when dealing with different problems such as those of a physical nature or those of a social nature. For the researchers this provided support for the utility of assessing coping in general with a chronic illness rather than with regard to a specific problem or specific time period.



#### 1.4.1 Coping with MS

Chronic illnesses like MS could be construed as lifelong enduring stressors that require considerable long term coping efforts by those who are afflicted. As MS is characterised by gradual or sometimes sudden deterioration over a long time span, how one copes may be influenced by the particular stress at a specific time point i.e. coping with a sudden loss of mobility. Alternatively, individuals with MS may employ enduring styles of coping in dealing with the challenges that the illness brings.

Previous studies of coping in MS have been predominately descriptive (O'Brien, 1993; Sullivan, Samuel & Weinshenker, 1997; Warren, Warren & Cockerill, 1991). For example, Warren *et al.* (1991) found patients experiencing an exacerbation of symptoms used more emotion focused coping as opposed to problem focused coping. In one of the few studies to utilise a control sample, Jean, Paul & Beatty (1997) compared differences in MS patients coping and the coping of their friends or relatives. They assessed the difference between how individuals coped with a specific MS problem compared to a general stressor. Minor differences were found between coping with the two types of stressors, although results indicated that when coping with a disease related stressor, patients were more apt to endorse strategies that involved accepting responsibility and escape-avoidance. No differences were found between patients and controls with regards to a general stressor suggesting that the strategies they used to deal with the illness were not generalised to other stressors.

An increasing number of studies have been interested in the mediating effect of coping in predicting psychological adjustment to MS (Jean, Paul & Beatty, 1999; Pakenham, Stewart & Rodgers, 1997). Pakenham *et al.* (1997) assessed how individuals with MS coped with the physical and psychosocial problems associated with MS. Findings suggested that emotion focused coping (particularly avoidance) was related to poorer adjustment. An interesting relationship was found between wishful thinking and patients appraisal of their health. When the main problem was physical, a greater degree of wishful thinking was utilised, but did not relate to higher levels of distress,

perhaps suggesting that wishful thinking may help some patients reframe their physical problems more optimistically. A later study by Pakenham (1999) assessed how individuals with MS coped in general (dispositional approach) with the problems associated with MS, and found that emotion focused coping was associated with greater levels of distress. Similar findings emerged from a study by Jean *et al.* (1999), although they assessed coping with regard to a specific stressful experience associated with MS.

Other studies have assessed coping qualitatively, for example McCabe (1996) and found similar findings to those listed above. Although most of the studies have found consistent relationships between coping and distress (Jean *et al.* 1997, 1999; Mohr, Goodkin, Gatto & Van Der Wende 1997; Pakenham *et al.* 1997) one study found no evidence for an association of coping strategies and distress (Wineman, Durand & Steiner, 1994), and found instead that demographic and illness variables were more important predictors of distress.

#### **1.4.2 Coping with caring for a disabled relative**

As noted above, demands placed on carers can be considerable, and much research has been conducted on assessing which individuals are most at risk for experiencing distress. Although patient factors (degree of disability) and carer factors (gender, age, relationship to care recipient) have provided some indication of who is most at risk, they do not totally explain the variance in individual adjustment.

Findings from studies that have examined caregivers of both dementia sufferers and of those with a brain injury have been consistent with findings in the general coping literature. Poorer caregiver adjustment has been found to be related to reliance on passive, avoidant emotion focused coping (Sander, High, Hannays & Sherer, 1997; Walsh, Blanchard, Kremer & Blanchard, 1999).



### **1.4.3 Coping with MS caregiving**

Arguably the unpredictable and progressive nature of MS, is a considerable challenge for those caring for the patient. As noted, a patient's physical status may deteriorate over night and the carer may be faced with an increased burden of care, which may result in significant reorganisation of their domestic and occupational routine. Alternatively, a patient's decline may be more gradual and provide time for the carer to prepare. How carers cope with each new stress will ultimately predict the extent to which they are distressed.

O'Brien (1993) examined the coping strategies of MS caregivers and found that caregivers utilised equal levels of emotion focused and problem focused coping, and that both forms of coping were associated with an increase in caregiving strain. Knight *et al.* (1997), assessed caregivers perception of coping effectiveness and found this to be one of most significant predictors of burden, however in this study coping was assessed using only three questions. Pakenham (1998) found couples who used higher levels of problem focused coping and lower levels of emotion focused coping were less distressed at one year follow up. However, one study found contrary to this, that coping strategies caregivers used were unrelated to caregiver adjustment (O'Brien, 1995). However, this finding may have resulted from the coping measure (F-COPES) which has not been widely used in coping research.

### **1.4.4 Summary of findings on coping in MS**

Apart from the few studies referred to above, there has been little research on coping with MS or coping with MS caregiving. However, there appears to be some degree of consensus with other studies with other chronic diseases, i.e. that emotion focused coping is associated with poorer adjustment. The role of problem focused coping remains unclear.

While the present study aims to further elucidate the importance of coping in MS, it aims to address some of the methodological difficulties. A formal coping measure

will be used (Revised Ways of Coping Checklist) devised by Vitaliano, Russo, Carr, Maiuro (1985). Additionally, individuals will be asked during a semi-structured interview how they coped with MS. Furthermore, as evidenced above, coping with a chronic illness has been assessed in a variety of ways; how people cope with a specific aspect of the illness, or how they cope over a specific time period. The present study is interested in assessing how patients and partners cope with a specific stressor (MS), but how they cope in general (dispositional) with the ongoing stress (Pakenham, 1998).

#### **1.4.5 Gender differences in coping**

It is widely held that men and women cope in different ways. This assumption is based upon cultural stereotypes and the developmental literature (Fitting *et al.* 1986). Men for example are often construed as problem solvers, whereas women put a stronger emphasis on their personal relationships, social support and expressing emotion. Empirical research has confirmed this hypothesis in relation to a variety of stressors. In her study of marital coping, Bowman (1990) found that women reported more worry, conflict and seeking out of distracting activities as a response to marital problems. Similarly, Lussier, Sabourin & Turgeon (1997) found women used significantly more emotion focused coping and avoidance strategies than men. However no differences were found between task-orientated (problem focused) coping.

#### **1.4.6 Gender differences in coping with caring**

With regard to caring for a disabled spouse, women have been found to use more avoidant coping strategies whereas men used more problem-focused strategies (Barusch & Spaid, 1989). Furthermore, Zarit *et al.* (1986) suggest that men may have different strategies for dealing with dementia sufferers which enable them to distance themselves from everyday problems. They observed that husbands often utilised a more instrumental approach to daily problems. Billings & Moos (1981) reported that women caregivers were more likely to use "avoidance coping", which was considered

maladaptive and concluded, as did Pearlin & Schooler (1978), that women tend to use less effective coping methods than men. Most differences between men and women are relatively small and many of the differences in coping do not emerge consistently across studies.

#### **1.4.7 Age differences in coping**

Research has produced conflicting findings with regard to age differences in coping. In one of the earliest studies to examine age and coping, Pearlin & Schooler (1978) indicated that older people's coping strategies were different from, and less effective than younger people's. However, Folkman, Lazarus, Pimley & Novacek (1987) found no age differences in coping in their sample of 45-64, although, arguably this is not a larger enough age range to ascertain differences. In her study of marital coping Bowman (1990) found coping efforts varied with age/years married. The use of positive approach fell to its lowest level in the 40 year old group then rose to its highest level with increasing age.

With regard to coping with chronic illness, Scholl, Harlow, Stolbach & Brandt (1998) found that age was not a significant predictor of distress when younger and older women coping with breast cancer were compared. With regard to coping with caring for a husband with Alzheimer's disease, Kramer (1993) found that younger age was positively associated with more problem focused coping.

It is important to be cautious when drawing conclusions from cross-sectional studies, as the changes in coping may reflect cohort based shifts in coping styles and differences between stressors and the meaning of stressors for individuals (Felton & Revenson, 1987). More specifically, coping with an illness when one is younger, may be different to when one is older, perhaps due to the expectation of declining health when one is older, and also the absence of fewer social and financial stressors.

### **1.5.0 Coping in couples**

Until recently, coping research has focused primarily on the coping of individuals in stressful situations. The analysis has rarely extended beyond the individual level of analysis, despite the fact that many stressors have an interactional dimension to them. This is particularly so with regards to chronic illness, where the illness can have psychological consequences on both the patient and their partner (Revenson, 1994). While there is some evidence to suggest that distress in one partner can be linked with distress in the other, so too may the coping strategies each member brings to bear during the stressor (Ptacek & Dodge, 1995). Kotchick, Forehand, Armistead, Klein, & Wierson, (1996) note that:

maladaptive coping by one family member may have an adverse effect on the psychological functioning of other family members by increasing the level of distress experienced by the individual using such coping strategies, which in turn has negative effects on the functioning of other family members (p.359).

Unfortunately, like other attempts (Bodenmann, 1995) to define couple coping, this statement is opaque, and no attempt is given to provide examples of couple coping. The few theoretical models of stress and coping in larger systems (families) have not been applied to intimate dyads.

### **1.5.1 Couple coping in chronic illness**

Although the illness and the consequence of the illness can be perceived as a stressor for the couple as a whole, elements of the stressor may be shared and others may affect either the patient or partner separately. For example, shared stressors may include the impact the illness has on their social life, sexual functioning and loss of income. Additionally, each member of the dyad may have to cope with different stressors; the patient with ongoing pain, and disability; the spouse with the magnitude

of caring for his/her partner. There is limited research on couple's coping in chronic illness.

One approach that has been proposed to assess couple coping has been referred to as 'coping congruence' (Barbarin, Hughes, & Chesler, 1985; Pakenham, 1998; Revenson, 1994).

### **1.5.2 Coping congruence**

Coping congruence emphasises the similarity or dissimilarity between partners coping as a predictor of adaptation (Revenson, 1994; Pakenham, 1998). According to Revenson (1994) illness can be conceived as a stressor which exerts a disorganising influence on the couple, requiring a reorganisation of coping. More specifically, couples who use similar coping strategies may find it easier to contend with new stresses, as coping is more co-ordinated and mutually reinforcing. On the other hand, the use of dissimilar types of coping may also be effective as the couple may have access to a broader range of coping strategies and one partner's coping may enhance the other's efforts (Revenson, 1994). Revenson & Cameron (1992) employed a congruent approach with couples with musculoskeletal or rheumatic disease. Using cluster analysis, findings indicated that dissimilar coping styles did not result in a greater level of psychological distress.

A similar finding was found in a study of married couples coping with their children's cancer (Barbarin *et al.* 1985); similarity in problem focused coping was associated with poorer marital adjustment and similarity in the use of optimism (an emotion focused strategy) was related to a better marital outcome. From these findings, Barbarin *et al.* (1985) concluded that marital functioning may be enhanced when the couple is dissimilar with respect to problem focused coping and similar with respect to emotion focused coping. However, no formalised coping measure was used in this study.

Ptacek & Dodge (1995) assessed the impact of coping similarity on marital satisfaction in middle-aged married, and student dating couples. To assess similarity, between partners, they computed an average absolute difference score. This was the difference between couples scores on the COPE (Carver, 1989) in terms of problem focused, emotion focused and 'less useful' (venting emotions, alcohol-drug use) coping. On the whole, they found that couples with a more similar coping style were more satisfied with their relationship than couples with a dissimilar coping style. This pattern held regardless of the coping strategy (problem or emotion focused). However, the pattern of correlation was not consistent across samples. In the student sample the strongest correlation with satisfaction was similarity in the use of less useful coping, whereas for the middle aged sample similarity in both forms of coping was associated with husband's satisfaction. Interestingly, wives satisfaction was largely unrelated to similarity in coping.

### **1.5.3 Couples coping with MS**

To date only one study has examined couples coping with MS (Pakenham, 1998). Pakenham (1998) examined the congruence (or similarity) between patient and caregiver's coping strategies in relation to distress. Congruence was examined separately for emotion focused and problem focused coping. In a similar manner to Ptacek & Dodge (1995), Pakenham (1998) calculated congruence by assessing the difference between partner's scores on both emotion focused and problem focused coping. Pakenham (1998) found greater differences between members in problem focused coping was related to lower levels of distress. However he found no support for the hypothesis that similarity in members use of emotion focused coping would be associated with lower levels of distress.



#### **1.5.4 Other couple coping approaches**

Other researchers have taken a different approach to assessing coping in couples and have examined the effect of one member of a couple's coping on distress in the other. For example, Coyne & Smith (1991) examined couples coping six months after the husband's heart attack. Wives who used avoidant coping regarding their husband's illness were more likely to be distressed. Furthermore, patient's avoidance in discussing the stressor was also associated with greater distress in their wives when the avoidance occurred in the context of a poor marital relationship. Manne & Zautra (1990) examined female rheumatoid arthritis patients and their husband's coping and distress. Husband's criticism was associated with greater distress and maladaptive coping in wives. A more recent study Ey, Compas, Epping-Jordan & Worsham (1998) found that when the husband had cancer, his avoidant coping was significantly predictive of his wife's self-reported symptoms of anxiety or depression.

#### **1.5.5 Summary**

Only a few studies have examined coping congruence and findings have been conflicting. Some studies found similar styles of coping in couples are related to better adjustment (Ptacek & Dodge, 1995) while others have found the reverse (Barbarin *et al.* 1985; Revenson, 1994). Furthermore, the results of some studies suggest that the degree to which couple coping is similar or dissimilar is predicted by the type of strategy studied (Barbarin *et al.* 1985; Pakenham, 1998).

While it cannot be denied that investigating what people do in specific situations will help us understand what moderates distress, little is known about what people do in general with regard to a life long stressor such as chronic illness. As an important predictor of well being and mental health in persons who experience chronic illnesses, Volrath, Torgensen & Alnaes (1995) note that if coping is to predict long term mental health, it has to be at least moderately consistent over time and across situations. The present study aims to investigate how individuals and their partners cope in general with MS, and to assess the degree to which couple coping is related to patient and

partner distress. Like Pakenham (1998) the present study is interested in couple coping, however unlike Pakenham, the present study aims to assess only couples who are in a marital or co-habiting relationship. This is to assess how individuals in an intimate and confiding relationship are affected and cope with a chronic illness.



### **1.6.0 SOCIAL SUPPORT**

Social support has been defined in different ways, although all definitions are based on the assumption that people must rely on one another to meet certain basic needs. Hirsch (1980) for example defines it as the degree to which the individual's needs for socialisation, tangible assistance, cognitive guidance, social reinforcement, and emotional sustenance are met through interaction with the social network. Other theorists define it in terms of the fulfilment of specific needs in the event of adverse circumstances. On the whole, how social support is defined is reflective of the two prominent models of social support; the main effect model and the buffering model:

#### **1.6.1 Models of social support**

##### **(a) Main effect model**

This model emphasises the importance of relationships with others to enhance well being. A key assumption is the fulfilment of ongoing social needs. Weiss (1974), for example proposes six different functions that relationships with others provide; attachment, social integration, reassurance of worth, guidance, reliable alliance (knowing others will offer assistance when needed) and nurturing (feeling needed by another). These functions are conceptualised as ongoing requirements for well being and have a beneficial effect irrespective of whether persons are under stress. This model is often described in terms of the structure of social support and includes marital status, the extended family, work, and community. Main effects are thought to stem from a sense of well-being due to group acceptance, offers of aid, and stable, predictable environments (Berkman, 1985).

##### **(b) Buffer model**

This buffer model focuses on aspects of social support which act as a 'buffer' against the effects of stress. It posits that support 'buffers' or protects persons from the potentially damaging influence of stressful events. It concentrates on the functional components of social support which includes overall quality of social relationships (Blazer, 1982; House & Kahn, 1985), social companionship (Wills, 1985), esteem,

instrumental support (Wills, 1985) and the timing of social support (Cohen & Syme, 1985b). The primary benefit of social support is protection against the deterioration of well being that may have been caused by the pressures of stressful events. In this model social support is only beneficial under conditions of high stress- when stress levels are low, social support is unrelated to well being. The findings of the seminal study of Brown & Harris (1978) could be viewed as support for this model; the presence of an intimate relationship in women facing stressful events was related to a lower incidence of depression.

### **1.6.2 Social support and mental health**

Findings from studies that have used these two models are at times inconsistent, but they tend to provide empirical support for both models. In general when coping with life stress, the presence of social support has been associated with better physical and mental health in both normal and impaired populations (Berkman, 1985; Cohen, 1988; Cohen & Willis 1985). Brown, Bifulco, Harris, Adler & Bridge (1986) found social support to be a significant predictor of depression when individuals were assessed longitudinally. Perception or satisfaction of social support has been identified as a key factor in distinguishing those who are distressed from those who are not. Results from a large number of studies suggest that there is a positive association between perceived social support and well being (Swindells, Mohr, Justis, Berman, Squier, Wagener & Singh, 1999). The relationship between received or actual social support is less strongly associated with well being (Wethington & Kessler, 1986).

### **1.6.3 Social support and chronic illness**

Social support is important for both those with a chronic illness and their partners or carers. For patients, it is often the spouse who is the main source of both practical and emotional support, whereas for the partner, the support gained from the marital relationship may be reduced depending on the patient's emotional and physical problems. Furthermore, as the dependency needs of the patient increase, caregivers may have less time and energy to maintain their own social networks. Although it

may be assumed that the amount of support received either from the family or outside agencies would be related to lower levels of distress in either patients or partner, the research has been conflicting. As noted above one of the most consistent findings in the literature is that perception or satisfaction with support is a better predictor of distress than the actual amount of help received (Sander *et al.* 1997).

With regard to caring for those with a chronic illness, much of the research has been conducted on those caring for a relative with dementia. Gilhooly (1984) assessed social support in terms of both the frequency of contact with friends and family and the satisfaction with support. Interestingly, her findings indicate that although the amount of help and contact from family and friends was not significantly associated with caregiver's well being, a significant relationship was found between carer's satisfaction with support and their psychological well being.

#### **1.6.4 Social support: MS patients and MS caregivers**

Depending on the nature of the disability of the care recipient and the resources available in the community, couples may spend increased time with each other in the home and consequently less time in activities outside the home and with other people (DesRosier, 1992; Foxall *et al.* 1986). Foxall *et al.* (1986) found that increased social contacts by telephone or in person resulted in significantly higher psychological adjustment for both partners.

Although there are various support resources (such as the MS society) available that both patient and carer may utilise, it is not yet clear to what extent MS patients and their families utilise these supports. Various home services such as home helps or nurses or rehabilitation services may provide practical support. Utilisation of these services may depend on the individual's perception of strain as well as their satisfaction with the informal support they receive.

Research suggests that the average network size of people with MS is small, and that the spouse is the main source of support (O'Brien, 1993). O'Brien (1993) also examined MS patient's satisfaction with support and found greater satisfaction with emotional support, but not practical support. Perhaps not surprisingly an association was found between satisfaction with support and degree of disability, and the more disabled patients were the least satisfied, suggesting that they may have become isolated as a result of the illness. Other studies have indicated that when MS patients have contact with non-disabled individuals (Maybury & Brewin, 1984) and perceive family and friends to be supportive (McIvor *et al.* 1984) a better psychosocial outcome is indicated. However, Wineman (1990) found no relationship between MS patients perceived support of their social networks, but found that patients with a stronger 'will to live' were characterised as having stronger network bonds.

Good, Bower, & Einsporn (1995) examined social support in a group of spousal caregivers, and found that social support was low, and that female caregivers used self help groups and friends to a significantly greater extent than males. Interestingly, there was a relationship between social support and the number of individuals in the household; caregivers in households with more members had lower perceived support, perhaps suggesting that it is not the amount of support available, but the quality of that support. In a study that examined the factors that accounted for MS caregiver general health, O'Brien (1995) found that satisfaction with social support explained very little of the variance in caregiver outcomes, but more explanatory was objective and subjective burden, and perceived uncertainty about the illness.

In line with the literature that has found perception or satisfaction of support to be an important factor in both patient and partner well being, the present study aims to examine the relationship between satisfaction with support (emotional and practical) and levels of distress.

### **1.6.5 Social support and coping in chronic illness**

Despite the potential mediating effects of social support and coping, there are few studies investigating their combined effect in chronic illness (Schreurs & DeRidder, 1997). Schreurs & DeRidder's note that the failure to take account of the interactive effects of these two theoretical concepts constitutes the most significant shortcoming in this area of research. Sollner, Zschocke, Schir, Stein, Rumpold, Fritsch & Augustin (1999) investigated the effects of the combined patterns of social support and coping style in cancer patients and found that high social support combined either with active coping, or stoicism was associated with good adjustment, whereas low perceived support and a passive coping style was associated with poor adjustment.

### **1.6.6 Aims of the present study**

While there has been much research establishing that MS is associated with higher levels of distress, little is known about the effects on the marital or cohabiting partner. One of the aims of the present research is to both extend past research on patients with MS by assessing levels of psychological distress, and also to contribute to the literature by examining partner caregivers psychological distress. An additional aim is to assess the amount of strain (subjective and objective ) caused by the illness for both patient and partner.

The principal objective of the present study is to draw together the factors that have been identified in the research literature as contributing to both patient and partner distress. Theoretical constructs such as coping and social support have been highlighted as well as the influence of certain illness related variables (length of diagnosis and level of disability) and demographic variables (gender and age). Furthermore, the present study aims to add to the research literature in this area by examining other factors such as the association of distress between partners, as well as the influence of couple coping as a potential mediator in both patient and partner distress. The influence of these variables will be assessed independently for patient and partner. Finally, this study aims to complement the quantitative analysis with

qualitative information, gathered at semi-structured interviews regarding the effects of MS, how couples cope and couples perception of relationship satisfaction.

### **1.7.0 HYPOTHESES**

#### **Distress**

1. MS patients will have higher levels of distress than their partners as measured by the HAD (anxiety and depression scales) GHQ 28 and the Strain index (CSI).
2. Patients and partners levels of distress as measured by the HAD (anxiety and depression) and GHQ 28 will be positively correlated; patients with high levels of distress will also have partners with high levels of distress.
3. Length of diagnosis, severity of disability and age will not be associated with distress as assessed by the HAD (anxiety and depression) in either patients or partners.
4. There will be gender differences between patients and partners. Female patients and partners will have higher levels of distress as measured by the HAD (anxiety and depression) and GHQ 28 than male patients and partners.

#### **Coping**

5. Higher levels of anxiety and depression will be found in patients and partners who use higher levels of emotion focused coping.
6. Greater discrepancies in problem focused coping in couples will be related to lower levels of anxiety and depression in patients and partners.

#### **Social support**

7. Greater dissatisfaction with emotional and practical social support in patients and partners will be related to higher levels of anxiety and depression as measured by the HAD.



## **2.0 METHOD**

This study was approved by the Forth Valley Ethics Committee in December 1999, and Fife Health Board of Ethics in March 2000.

### **2.1.0 Design**

A cross-sectional within and between subject design is used. Qualitative data are thematically analysed. For the most part, throughout the analysis one tailed significance tests will be used to test the experimental hypotheses. For all additional and post hoc analyses, a two tailed significance was employed. A significance level of 0.05 was used to determine whether hypotheses were supported. For the purposes of clarity, those people who have MS, will be referred to as 'patients' and husbands/wives as 'partners'.

### **2.2.0 Recruitment**

Participants were initially recruited from the Area Rehabilitation Service at Stirling Royal Infirmary, and later from Fife Rehabilitation Service at Cameron Hospital, Leven, Fife. These services are interdisciplinary and multi-disciplinary respectively, which include input from a range of professionals, including Doctor, Occupational Therapy, Physiotherapist, Nurse, Dietician, Speech and Language therapist, and Clinical Psychology. Both services were developed approximately three years ago.

Participants were selected from both services according to the following criteria:

- A diagnosis of 'probable' or 'definite' MS of at least 2 years
- Have the cognitive ability to be interviewed and complete the questionnaires
- Be in a co-habiting relationship of at least two years duration
- No history of any major psychiatric disorder or history of substance abuse to be present in patient or partner.
- Partner currently helping with activities of daily living (i.e. active caregiver).



To assess whether patient's met the inclusion criteria, files were checked and when information was absent, team members were asked to provide more information about the individual and their living circumstances.

### **2.3.0 Procedure**

A letter, which described the nature of the study and a research information sheet, was sent to couples (see Appendix 1). If participants wished further information about the study they were encouraged to contact the author (EC). Also, enclosed was a response sheet, which asked participants to complete and return in a stamped addressed envelope, indicating whether or not they wished to participate. When responses were received, couples were telephoned and an appointment time was arranged. Participants were offered the choice of a hospital or home visit.

At appointment, the nature of the research was explained, and couples were invited to ask questions. Following this, separate consent forms were signed and witnessed by the author, and couples were provided with a copy. The joint interview, designed to gather demographic details, and build rapport was administered first. A semi-structured interview was then conducted with partners, and the questionnaires listed below were then provided. While partners were completing their questionnaires, a semi-structured interview was conducted with patients, and the same questionnaires were provided. The rationale for this administration procedure was to ensure that participant's responses were not influenced by the presence of their partner. Furthermore, in a pilot study conducted prior to the study, it was observed that many patients with MS had visual and motor problems that made independent completion of questionnaires difficult. Therefore, it was felt that the best use of the time was to interview partners first, to allow time to provide help to MS participants. When participants had visual or motor problems, administration of questionnaires was oral. Participants were given enlarged cue cards with the responses listed, and the

researcher emphasised the need to respond as if completing a written questionnaire, and discouraged discussion of each item.

The questionnaires were administered in the following order: MMSE, HAD, RWCC, SOS-B, GHQ, CSI for both patients and partners (apart from MMSE). This was so that more demanding questionnaires (RWCC) and (SOS-B) were administered first, to ensure concentration was maximised.

#### **2.4.0 Measures**

##### **(a) Measures of distress**

**General Health Questionnaire 28** (Goldberg & Hillier, 1979).

This measure was designed as a screen to differentiate psychiatric patients from those who are well. The original version comprised of 60 questions, but subsequent cluster and factor analyses, produced a 30, 28, and 12 item version. The different versions of the GHQ correlate well with each other (Goldberg, Kay & Thompson, 1976). All forms of the GHQ have been found to be valid and reliable. It is a frequently used research tool, which provides a general measure of severity and divides into four subscales; somatic symptoms, insomnia, social dysfunction and severe depression. The respondents are required to note if they have recently experienced a particular symptom or item of behaviour using a four point scale: "less than usual", "no more than usual", "rather more than usual" or "much more than usual". Two scoring methods have been proposed: in a likert form 0 1 2 3 or 0 0 1 1, which the authors recommend as this eliminates errors due to 'end users'. In this study the simple scoring method of the four response categories (0011) will be used. The threshold score of 5 and above was taken to indicate psychiatric caseness. The 28 item version is used here, as it was found by Rabins & Brooks (1981) to be a valid and sensitive instrument in detecting emotional morbidity in patients attending a multiple sclerosis clinic.

**Hospital anxiety and depression scale (Zigmond & Snaith, 1983).**

This is a 14 item scale which divides into two separate scales (anxiety and depression). It was developed for use with a non-psychiatric population and is a reliable instrument for screening clinically significant anxiety and depression. It was used here as it contains very few physical symptoms of anxiety or depression; thus limiting the possibility of confounding symptoms of distress with symptoms of MS. In their initial study, Zigmond & Snaith (1983) assessed the psychometric status of the measure and found it to have good face, content, and criterion validity. Significant associations were also found for internal consistency. The authors initially suggested that scores between 8-10 are likely to be obtained by mildly disturbed clients ('doubtful cases'), scores between 11-21 were likely to indicate definite anxiety or depression (or cases). The authors later suggested that it can be used as a measure of a severity of the states, and recommend four score ranges. 'Normal' scores fall between 0-7, 'mild' 8-10, 'moderate', 11-14, and 'severe' 15-21. In the present study, a score of 8 and above was used to differentiate cases from non cases.

**Caregiver strain index (CSI) (Robinson, 1983).**

This measure was designed as a brief and easily administered screening instrument to identify strain in caregivers of recently hospitalised hip surgery and heart patients aged 65 and over. 13 stressors are listed and participants are asked to simply respond 'Yes' or 'No' to the following: inconvenience, confinement, family adjustments, changes in personal plans, competing time demands, emotional adjustments, upsetting behaviour, personality changes, work adjustment and feeling overwhelmed. The psychometric properties of this measure were established by the authors who found significant levels of internal consistency and construct validity. Although it was designed for this population, the authors suggest more widespread use in other groups of caregivers.

O'Brien (1993) adapted the questionnaire for her sample of MS caregivers and although retaining the original 13 items, included a likert scale for each item. This scale asks participants 'how stressful' each item was on a five point scale, ranging from

'not at all' (0) to 'extremely' (4). O'Brien (1993) conducted no reliability or validity analysis. However, she found it to be a useful measure with good face validity (personal communication).

O'Brien's (1993) version of the scale was used with partners and the wording of the scale was adapted for use with patients. However, before using it in the present study, it was piloted on 3 MS patients who felt that the wording was appropriate, and no changes were made.

### **(b) Measure of social support**

**Significant others scale-B (SOS-B)** (Power, Champion & Aris, 1988).

This measure was designed to provide a measure of both perceived emotional and practical support. For each participant, six scores can be calculated:

1. Actual emotional support
2. Actual practical support
3. Ideal emotional support
4. Ideal practical support
5. Discrepancy between actual and ideal emotional support
6. Discrepancy between actual and ideal practical support

Power *et al* (1988) provide both a long and a short version of the questionnaire, although the authors recommend the short version when other measures are to be administered. The scale is useful as it allows the individual to state his/her own optimum level of support rather than imposing normative values of how much support each person should have (Power *et al.* 1988). The validity of the SOS-B was established by concurrent and construct methods. To establish concurrent validity the authors assessed a symptom free group, non-depressed cases, and depressed cases, using the GHQ 28 and the SOS-B. Significant differences were found between the depressed and other two groups on these measures suggesting that the SOS-B could discriminate in a predicted fashion between the groups. Construct validity was

assessed using factor analysis. The short version of the questionnaire is used in the present study.

**(c) Measures of impairment/disability**

**The Mini-Mental State Examination (MMSE)** (Folstein, 1975).

This is widely used screen of cognitive impairment. A cut off of 23 is recommended to exclude cognitive impairment.

**Barthel Activities of Daily Living (ADL) Index.** (Mahoney & Barthel, 1965).

This was used to assess level of physical disability. This is a well validated 10-item measure of ability to perform basic activities of daily living (e.g. feeding, dressing, walking, bathing, toileting and bowel function). Scores range from zero (maximum disability) to 20 (independence). Patient's scores can be classified in terms of severity of disability:

0-4	very severely disabled
5-9	severely disabled
10-14	moderately disabled
15-19	mildly disabled
20	physically independent, but not necessarily normal or socially independent

**(d) Coping measure**

**Revised Ways of Coping Checklist - (R-WCC)** Vitaliano, Russo, Carr, Maiuro & Becker (1985).

This questionnaire is a revision of Lazarus & Folkman's (1984) original Ways of coping questionnaire. Like its predecessor, it contains a wide range of thoughts and actions (coping strategies) that people use to deal with the demands of a specific stressful encounter. This measure was utilised in the present study as it contains only

42 coping items, and is much shorter than other coping scales (which typically contain upward of 50 items).

The re-factored scale (Vitaliano *et al.* 1985) comprises five factors:

- |                        |  |
|------------------------|--|
| Problem focused:-      | 'Made a plan of action and followed it'<br>'Came up with a couple of different solutions to the problem'           |
| Seeks social support:- | 'Accepted sympathy and understanding from someone'<br>'Talked to someone who could do something about the problem' |
| Blamed self:-          | 'Realised I brought the problem on myself'   |
| Wishful thinking:-     | 'Hoped a miracle would happen'<br>'Wished I could change the way I felt'   |
| Avoidance:-            | 'Avoided being with people in general'<br>'Tried to forget the whole thing'  |

Although designed to assess process coping, coping style can be assessed by changing the wording from how one copes with a specific stressor and how one copes generally (coping style) (personal communication from Vitaliano, 1999). The trait version was used in the present study to allow assessment of a similar general stressor: MS. Previous research in coping suggests that when the state measure is applied, each individual's stressor can vary considerably, thus making comparison of coping difficult.

The wording of the instructions in the present study for patients was:

'Please think about how you generally cope with the problems associated with MS. The items below represent ways that you may have dealt with these problems. Please place the appropriate number after each statement to indicate the degree to which you used each of the following thoughts/behaviour to deal with your problems'

The wording on the partner's questionnaire was identical apart from a change in wording to 'generally cope with the problems associated with living and caring for someone with MS'.

Participants were asked to rate if they 0- have never used , 1- rarely used, 2- sometimes used, and 3 regularly used the coping strategy.

In some studies, 'problem-focused' and 'seeks social support' are formed together to make the 'problem focused coping scale', and 'blamed self', 'wishful thinking' and 'avoidance' are formed to make the 'emotion focused coping scale' (Pakenham, 1998). This procedure will be used in the present study.

### **2.5.0 Demographic information**

This information was collected at the joint interview and included: date of birth, age and time since diagnosis, course of MS and demographic category.

#### **Deprivation category (Carstairs & Morris, 1991)**

Deprivation categories refer to a simple (unweighted) combination of the following four variables: no car, male unemployment, overcrowding and social class IV and V. Categories range from 1 (most affluent) to 7 (most deprived). Each postcode is allocated a deprivation category and Carstairs & Morris (1991) provide deprivation categories for all health boards areas in Scotland. Deprivation category is believed to be more a sensitive indicator of a person's status, as opposed to social class.



### **2.6.0 Semi-structured interview questions**

The following questions were asked at individual interviews with patient and partner:

#### **Patient**

What effects (positive and negative) has MS had on your life?

What are the important things that have helped you cope with your MS?

Has MS had an impact on your relationship? If so? How?

How happy are you with your relationship? (5 point likert scale)?

#### **Partner**

What effects (positive and negative) has helping your partner had on your life?

What are the important things that have helped you cope with your position?

Has MS had an impact on your relationship? If so, in what way?

How happy are you with your relationship? (5 point likert scale)?

Participants were encouraged to complete the questionnaires when the researcher was present, although on several occasions, time was limited and in this event a stamped addressed envelope was provided for the participants to return the questionnaires.

Following the initial appointment, the participants General Practitioner was informed of their participation.

### **2.7.0 Data analysis**

Data was analysed using a Statistical Package for the Social Sciences (SPSS) Version 9 for Windows 1998. Initial analysis calculated group means and standard deviations for MS patients for time since diagnosis, level of disability. Means and standard deviations were calculated for patients and partners for psychological distress, coping and social support. To assess differences between patients and partners, independent t tests and Mann Whitney tests were conducted. In addition, the relationships between



variables were analysed using Pearson product-moment and Spearman Rho correlations and multiple regression. Post hoc analysis were completed on variables of interest using a 0.05 level of significance. Finally, a thematic analysis was conducted on the information provided at semi-structured interviews.

To ensure confidentiality, each participant was assigned an identification number, which was entered into the computer. Participant names were removed from all interview schedules once data collection had been completed.

## **3.0 RESULTS**

### **3.1.0 Recruitment**

Fifty-seven couples were invited to participate in the study. 42 couples agreed to take part (i.e. a recruitment rate of 73%). Of the participants who did not respond to the invitation to participate, when reasons were given they included: hospitalisation of patient, or unwillingness of either patient or carer to participate. Thirty seven couples (from 47 letters sent) were recruited from the Area Rehabilitation team at Stirling Royal infirmary, and 5 (from 10 letters sent) were recruited from Fife Rehabilitation service. All but one couple were interviewed at home. This dyad opted for a hospital based interview as this coincided with another appointment at the hospital.

### **3.1.1 Patient characteristics**

Table 1, below illustrates the characteristics of the patients who participated. From this table it can be seen that patients were predominately middle aged, all had been married for a number of years and the majority were female. Patients had been diagnosed for an average of 12.8 years (SD= 6.5) and had a mean Barthell score that was indicative of severe disablement (8.78 SD= 4.87). The majority of patients (69 per cent) were categorised between severely to moderately disabled. Furthermore, a considerable number of patients (85 per cent) were experiencing a secondary progressive course of MS.

### **3.1.2 Partner characteristics**

Partners were slightly older (51.57, SD=9.99) than patients and were more likely to be male (29) than female (13). While 42 were interviewed, three failed to complete some, or all, of the questionnaires.

## Patient characteristics

		N(%)	Average		SD	Range
			Mean	Median		
<b>Age</b>		42 (100)	49.47	--	8.13	36-63
<b>Gender</b>	<b>Males</b>	13 (31)	--	--	--	--
	<b>Females</b>	29 (69)	--	--	--	--
	<b>Years Married</b>	42 (100)	27	--	9.92	2-42
	<b>Deprivation category</b>	42 (100)	--	3	--	1-6
<b>Course of MS</b>	<b>S/P</b>	36 (85)	--	--	--	--
	<b>R/R</b>	5 (12)	--	--	--	--
	<b>P/P</b>	1 (3)	--	--	--	--
<b>Illness variables</b>	<b>Barthell</b>	42 (100)	8.78	--	4.87	0-17
	<b>MMSE</b>	42 (85)	27.38	--	1.86	24-30
	<b>Yrs diagnosed</b>	42 (100)	12.80	--	6.50	2-25
<b>Health board</b>	<b>Forth valley</b>	37 (88)	--	--	--	--
	<b>Fife</b>	5 (12)				

S/P=secondary progressive, R/R=relapsing/remitting, P/P= primary progressive.

**Table 1: Demographic and general characteristics of patients**

The literature suggests that when older MS patients are recruited, they tend to be diagnosed longer and are more severely disabled. To assess if this was the case for the present sample, Pearsons (2 tailed) correlations were conducted between years diagnosed, disability (Barthell index), and age. Age and years diagnosed were significantly associated ( $r=0.41$ ,  $p<0.01$ , 2 tailed), suggesting older patients were

diagnosed longer. In addition, a significant inverse relationship was found between age and the measure of disability ( $r = -0.32$ ,  $p < 0.05$ , 2 tailed), suggesting that older patients were more disabled. However, a significant relationship was not found for disability and years diagnosed ( $r = -0.27$ ,  $p = 0.08$ , 2 tailed), suggesting that the amount of years diagnosed was not necessarily suggestive of greater disability.

Overall, these correlations suggest that this sample largely comprised of patients who were older and had been diagnosed for a considerable amount of time. However, although older and more greatly disabled, the length of time they had been diagnosed was not associated with greater disability.

### 3.2.0 Exploratory data analysis

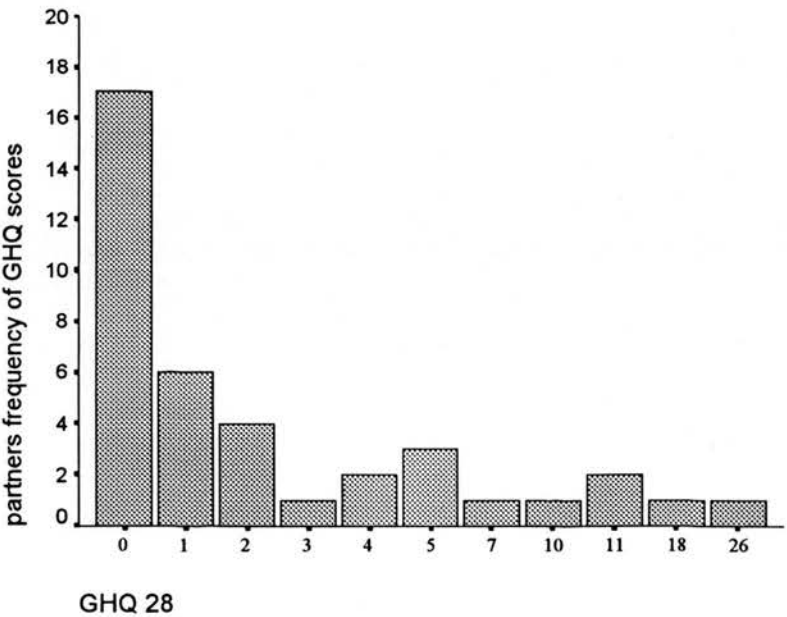
Exploratory data analysis indicated significant levels of skewness and kurtosis for the GHQ 28 for partners as illustrated below:

		Skewness		Kurtosis	
	No	Statistic	Std error	Statistic	Std error
GHQ (partner)	39	2.69	0.37	8.12	0.74

**Table 2: GHQ 28 for partners**

Figure 2 illustrates that the data were positively skewed with 43 per cent of partners scoring '0' on the GHQ 28. However, the presence of four outliers with scores of 26, 18, 11, and 10 appears to have inflated the mean (3.15, SD 5.47). In this instance the median (1) is perhaps a more accurate approximation of the central tendency.

**Figure  
2**



Non parametric statistics will be used to examine this variable when hypothesis testing and for any further analysis.

### 3.3.1 Hypothesis one: MS patients will have higher levels of distress than their partners as measured by HADS (anxiety and depression scales), GHQ 28 and CSI.

Table 3 below shows patient and partner mean and standard deviation scores and those meeting caseness (where appropriate) on each measure. It can be seen from this table that patients scores are higher than partners for all measures. However, caseness levels were only met for the mean GHQ 28 score for the group of patients. As indicated above, the GHQ 28 was not normally distributed for partners, therefore the median (1) was used in addition to the mean to provide a more accurate approximation of the average score.

Table 3 illustrates that a greater percentage of patients than partners met caseness for the three measures, although similar percentage caseness levels were found for anxiety (HAD-A). Within the two groups, 26 per cent of patients and 14 per cent of partners, scored in the moderate to severe range for anxiety (HAD-A). In addition, 19 per cent of patients and less than one percent of partners scored in the moderate to severe range of depression (HAD-D). Significant differences were found between the two groups on HAD-D, GHQ 28, CSI, but not HAD-A using independent t tests and a Mann Whitney test. The results are presented in table 3, below:

	Patients n=42			Partners n=39					
Measure	M	SD	% cases	M	SD	% cases	t/z	Df	1 tailed
HAD-A	7.59	3.92	45	6.85	3.87	41	0.86	80	0.20
HAD-D	6.71	3.65	43	4.50	3.41	15	2.83	80	0.01
GHQ 28*	6.30	6.36	43	3.15	5.47	23	-2.98	79	0.01
CSI	27.26	11.05	--	20.64	13.05	--	2.45	78	0.01

\*Mann Whitney U Test.

**Table 3: Independent and Mann Whitney tests of distress measures.**

Further analysis of the difference between patient and partners on each subscale of the GHQ 28 was conducted. As table 4 suggests below, significant differences were found between patient and partner on social dysfunction, severe depression, but not for somatic symptoms or anxiety/insomnia.

	Patient		Partner		z	Df	Sig (2tailed)
	M	SD	M	SD			
<b>Somatic symptoms</b>	1.42	1.80	0.94	1.71	-1.51	79	0.13
<b>Anxiety/insomnia</b>	1.11	1.74	0.94	1.68	-0.59	79	0.55
<b>Social dysfunction</b>	2.26	1.98	0.97	1.89	-3.49	79	0.01
<b>Severe depression</b>	1.50	2.14	0.28	1.16	3.48	79	0.01

**Table 4: Mann Whitney U Tests on the four subscales of the GHQ 28 for patients and partners.**

This result provides support for the hypothesis that patients have greater levels of distress compared to their partners. As HAD-A and GHQ 28 anxiety/insomnia subscale suggest no significant differences between groups, it appears that in this sample patients and partners distress differs with regard to the scales that measure depression (HAD-D) and severe depression (GHQ 28) as well as strain associated with the illness (CSI).



**3.3.2 Hypothesis two: Patients and partners levels of distress as measured by the HAD (anxiety and depression) GHQ 28, and CSI will be positively correlated; patients with higher levels of distress will also have partners with high levels of distress.**

To test this hypothesis, a two stage analysis of the data was conducted. The scores of the patients and partners were correlated as illustrated in tables 5 and 6 below:

Measures	Patients n=42		Partners n=39		R	Sig(1 tailed)
	M	SD	M	SD		
HAD-D	7.59	3.92	6.85	3.87	0.40	0.01
HAD-A	6.71	3.65	4.50	3.41	-0.03	0.42
CSI	27.26	11.05	20.64	13.05	0.25	0.06

**Table 5: Pearson correlations of patient and partner HAD and CSI scores.**

Measures	Patients n=42		Partners n=39		R	Sig(1 tailed)
	M	SD	M	SD		
GHQ 28	6.30	6.36	3.15	5.47	0.25	0.06

**Table 6: Spearman Rho correlations of patient and partners GHQ 28.**

As indicated in tables 5 and 6 above, a significant correlation was found for HAD-D. Correlations between patient and partner were not significant for HAD-A GHQ 28 or CSI, although the two latter correlations were approaching significance.

A closer analysis of the data was then conducted. The data were then categorised into patients who scored 8 and over on the HAD and 5 and above on the GHQ 28, and

patient scores were then correlated with their respective partner. This was to assess the association of distress between patients and partners when the patient met the criteria for caseness. Nineteen patients met the criteria for caseness on HAD-A (over 7), 18 patients met criteria for caseness on GHQ 28 (5 and over) and on HAD-D (over 7). Correlations were not significant for any of the measures, (HAD-D;  $r=0.37$   $p=0.06$ , GHQ 28;  $r=0.411$   $p=0.057$ , HAD-A;  $r=-0.81$ ,  $p=0.375$ ). However HAD-D and GHQ 28 were approaching statistical significance.

### **Summary**

The results of the above analysis provides partial support for the hypothesis that patients and partners distress is associated as indicated by the significant correlation of the HAD depression scale.

**3.3.3 Hypothesis three: Length of diagnosis, severity of disability and age will not be associated with distress as assessed by the HAD (anxiety and depression) in either patients or partners.**

Previous research has been equivocal with regard to the association between years diagnosed and level of disability and distress in MS patients. Therefore no direction was predicted and this hypothesis is two tailed.

**a) Patient analysis**

Table 7 and 8 show the results of correlations between years diagnosed and the distress measures. A Pearsons correlation indicated no significant correlations between level of disability, HAD-A or HAD-D.

Measure	N	M	SD	Pearson	Sig (2 Tailed)
HAD-A	42	7.59	3.92	0.08	0.59
Barthell	42	8.78	4.87		

**Table 7: 2 tailed pearson correlation of HAD A and level of disability (Barthell).**

Measure	N	M	SD	Pearson	Sig (2 Tailed)
HAD-D	42	6.71	3.65	0.23	0.14
Barthell	42	8.78	4.87		

**Table 8: 2 tailed pearson correlation of HAD D and level of disability (Barthell).**

No relationship was found for years diagnosed and HAD (A or D) as illustrated in tables 9 and 10 below:

Measure	N	M	SD	Pearson	Sig (2 Tailed)
HAD-A	42	7.59	3.92	-0.06	0.66
Yrs diagnosed	42	12.8	6.5		

**Table 9: 2 tailed pearson correlation of HAD-A and yrs diagnosed.**

Measure	N	M	SD	Pearson	Sig (2 Tailed)
HAD-D	42	6.71	3.65	-0.20	0.21
Yrs diagnosed	42	12.8	6.5		

**Table 10: 2 tailed pearson correlation of HAD-D and yrs diagnosed.**

#### **b) Partner analysis**

Although little research has examined the influence of patient illness factors, such as time since diagnosis and level of disability on partner outcomes in MS, research that has been conducted with carers of other chronic illnesses would suggest that these variables are not consistently associated with partner or caregiver outcomes.

Partners scores on HAD-A and HAD-D were correlated with level of disability, as illustrated in tables 11 and 12 below. The relationship between HAD-A and Barthell, almost reached significance. A significant negative correlation was found between Barthell and HAD-D, ( $r = -0.35$ ,  $p < 0.02$ ) suggesting that partners who were living with a more disabled patient had a higher depression score.

Measure	N	M	SD	Pearson	Sig (2 Tailed)
HAD-A	39	6.85	3.87	-0.30	0.06
Barthell	42	8.78	4.87		

**Table 11: 2 tailed pearson correlation of HAD-A and level of disability (Barthell).**

Measure	N	M	SD	Pearson	Sig (2 Tailed)
HAD-D	39	4.50	3.41	-0.35	0.02
Barthell	42	8.78	4.87		

**Table 12: 2 tailed pearson correlation of HAD-D and level of disability (Barthell).**

Again, partner's scores on HAD-A and HAD-D were not correlated with time since diagnosis, as tables 13 and 14 below indicate. This suggests that length of time patient is diagnosed is not associated with distress in the partner.

Measure	N	M	SD	Pearson	Sig (2 Tailed)
HAD-A	39	6.85	3.87	-0.08	0.60
Yrs diagnosed	42	12.8	6.5		

**Table 13: 2 tailed pearson correlation of HAD-A and yrs diagnosed.**

Measure	N	M	SD	Pearson	Sig (2 Tailed)
HAD-D	39	4.50	3.41	0.02	0.88
Yrs diagnosed	42	12.8	6.5		

**Table 14: 2 tailed pearson correlation of HAD-D and yrs diagnosed.**

#### **The association of age with distress**

To assess the potential influence of age with distress, age of patient and partner were correlated with HAD-A and HAD-D. Age of patient was not significantly correlated with either HAD-A ( $r=0.021$ ,  $p=0.89$ ) or HAD-D ( $r=0.17$ ,  $p=0.28$ ). Similarly no association was found between age of partner and HAD-A ( $r=0.02$ ,  $p=0.86$ ) or HAD-D ( $r=0.03$ ,  $p=0.85$ ).

Further analysis was conducted, and patients and partners were separated into two groups; those 45 and under and those over 46. The analysis considered patients and partners as one group. Independent t tests were conducted and no significant differences emerged for HAD-A ( $t=0.648$ ,  $df= 80$ ,  $p=0.519$ ) or HAD-D ( $t=1.51$ ,  $df=80$ ,  $p=0.135$ ).

**Summary**

Overall, these findings suggest that neither age, years diagnosed, or level of disability is associated with patients level of distress. For partners, age and years diagnosed were not associated with either HAD-A, or HAD-D. However, greater levels of disability in the patient was significantly associated with higher levels of HAD-D in the partner, suggesting that partners who were living with a more disabled spouse were more distressed.

**3.3.4 Hypotheses four:** There will be gender differences between patients and partners. Females (patients and partners) will have higher levels of distress as measured by the HAD (anxiety and depression) and GHQ 28 than male (patients and partners).

Separate analyses were conducted for patients and partners. Tables 15 and 16 below, illustrate that although female patients scored slightly higher on HAD anxiety and depression, there were no significant gender differences on any of the measures: (HAD-A, HAD-D and GHQ 28). However, this result should be viewed with caution due to the unequal numbers in the groups.

Measures	FEMALES N=29		MALES N=11		t	Sig (1 tailed)
	M	SD	M	SD		
HAD-A	7.79	3.64	7.15	4.61	0.48	0.32
HAD-D	7.03	3.56	6.00	3.89	0.85	0.20

**Table 15: Between group t tests on male and female patients on HAD-A and HAD-D.**

Measures	FEMALES N=29		MALES N=11		z	Sig (1 tailed)
	M	SD	M	SD		
GHQ 28	6.13	4.84	6.69	7.58	-0.11	0.91

**Table 16: Mann whitney U tests of males and female patient scores on the GHQ 28.**



Overall, significant differences were not found between female and male patients. In fact,, male patients mean scores on the GHQ 28 were higher than females, which is contrary to the direction expected.

**b) Female partners will be significantly more distressed than male partners.**

Tables 17 and 18 below indicate that female partners mean scores are higher than males on the HAD-A and HAD-D, however these differences were not significantly different when analysed using independent t tests. Although male partners GHQ 28 scores were higher than female partners, significant differences were not found when a Mann Whitney U test was conducted as illustrated in table 18, below.

	FEMALES N=13		MALES N=27			
Measures	M	SD	M	SD	t	Sig (1 tailed)
HAD-A	6.92	3.45	6.81	4.13	0.08	0.47
HAD-D	4.38	3.84	4.55	3.27	-0.14	0.44

**Table 17: Independent t tests between males and female partners scores on HAD A and D.**

	FEMALES N=13		MALES N=27			
Measures	M	SD	M	SD	z	Sig (1 tailed)
GHQ 28	1.53	2.25	3.96	6.41	-0.98	0.35

**Table 18: Mann Whitney comparisons of males and female partner scores on the GHQ 28.**

**Summary**

The analysis above indicated that there was no significant difference between male and females (patients and partners) on any of the measures of distress. However, caution is warranted when interpreting the results of the GHQ 28 as this measure was positively skewed.

### **3.3.5 Hypothesis five: Higher levels of anxiety and depression will be found in patients and partners who use higher levels of emotion focused coping.**

Before hypothesis testing, the coping subscales were inter-correlated to assess the viability of using two higher order scales 'emotion focused' and 'problem focused'. This analysis follows that of Pakenham (1998) and is consistent with the division of the scales in the literature.

#### **Inter-correlations of coping scales**

The five sub-scales: problem-solving, seeking social support, wishful thinking, avoidance and self-blame were examined. Two correlation matrices were conducted to assess the intercorrelations of the five subscales for patient and partner. All analyses were two tailed.

Non significant correlations were found for problem focused coping (PF) and wishful thinking ( $r=0.194$ ,  $p=0.223$ ), PF and blame self ( $r=0.031$ ,  $p=0.799$ ), and PF and avoidance ( $r=0.262$ ,  $p=0.09$ ) for the patient sample. Similarly, non significant correlations were found for PF and wishful thinking ( $r=0.085$ ,  $p=0.608$ ), PF and blame self ( $r=0.253$ ,  $p=0.120$ ), and PF and avoidance ( $r=0.021$ ,  $p=0.899$ ) for the partner sample. Seeks social support (SS) was correlated with blame self and found not to be significant ( $r=0.164$ ,  $p=0.307$ ), as was SS and wishful thinking ( $r=0.200$ ,  $p=0.08$ ), and SS and avoidance ( $r=0.229$ ,  $p=0.151$ ) for patients. Similar non significant correlations were found for SS and blame ( $r=0.150$ ,  $p=0.362$ ), SS and wishful thinking ( $r=0.085$ ,  $p=0.608$ ) and SS and avoidance ( $r=0.087$ ,  $p=0.597$ ) for partners.

Avoidance, wishful thinking, and self blame sub-scales were correlated with each other separately for patient and partner. For emotion focused coping, the mean sub-scale correlation for patient was  $r=0.52$ ,  $p<0.01$ , and the inter-correlations between the three emotion focused subscales are illustrated in table 19, below:

	Blamed self		Wishful thinking	
	r	p	r	p
<b>Wishful thinking</b>	0.44	0.01	- -	- -
<b>Avoidance</b>	0.49	0.01	0.64	0.01

**Table 19: Pearson correlations of emotion focused coping subscales for patients.**

The mean correlation of the emotion focused subscales for partners was  $r=0.50$ ,  $p<0.01$  as illustrated in table 20 below.

	Blamed self		Wishful thinking	
	r	p	r	p
<b>Wishful thinking</b>	0.45	0.01	- -	- -
<b>Avoidance</b>	0.48	0.01	0.57	0.01

**Table 20: Pearson correlations of emotion focused coping subscales for partners.**

Two Pearson correlations were conducted to assess the degree of correlation between the problem focused subscale and the social support subscale. For patients the correlation was  $r=0.40$ ,  $p<0.05$ , and for partners  $r=0.69$ ,  $p<0.01$ .

As avoidance, blame self and wishful thinking correlated positively with each other for both patient and partner, these were formed into an emotion focused coping scale. Similarly, because of the positive correlation between the problem focused and the social support sub-scale, these two scales were formed into a problem focused coping scale. The grouping of coping strategies on the Revised Ways of Coping Checklist into either problem or emotion focused scales is consistent with the two dimensions empirically derived from the original Ways of coping checklist (Lazarus & Folkman, 1984). Each scale had 21 items in each. The mean scores of the emotion focused (EF) and problem focused (PF) coping scale for patients and partners are presented below in table 21.

	Mean EF	SD	Mean PF	SD	t	Sig (2 tailed)
<b>Patient</b>	30.63	12.3	37.14	9.18	3.37	0.01
<b>Partner</b>	23.61	10.6	36.48	11.9	5.37	0.01

**Table 21: Within sample t tests on emotion focused coping and problem focused coping for patients and partners.**

Within group t tests were conducted to further explore the differences between the two types of coping in patients and partners. As table 21 above, illustrates patients and partners used significantly greater levels of PF coping compared to EF coping.

To test the hypothesis patients and partners scores on the HAD-A and HAD-D were correlated with their scores on the emotion focused coping scale. Table 22 illustrates the correlations for patients.

Measures	N	M	SD	r	Sig (1 tailed)
<b>HAD-A</b>	42	7.59	3.92	0.36	0.01
<b>EF</b>	42	30.63	12.30		
<b>HAD-D</b>	42	6.71	3.65	0.57	0.01
<b>EF</b>	42	30.63	12.30		

**Table 22: Pearson correlations of HAD-A and HAD-D with emotion focused coping for patients.**

As table 22 indicates, significant positive correlations were found between HAD-A and EF ( $r=0.36$ ,  $p<0.01$ ) and EF and HAD-D ( $r=0.57$ ,  $p<0.01$ ) for patients suggesting that higher distress is associated with a greater use of emotion focused coping.

Furthermore, this table suggests that correlations for HAD-D and EF coping are higher than for HAD-A.

In a similar analysis, partner HAD-A and HAD-D scores were correlated with emotion focused coping as indicated in table 23. Again, this shows a significant positive correlation was found for HAD-A and EF ( $r=0.38$ ,  $p<0.01$ ) and HAD-D and EF ( $r=0.57$ ,  $p<0.01$ ).

Measures	N	M	SD	r	Sig (1 tailed)
HAD-A	39	6.85	3.87	0.38	0.01
EF	39	23.61	10.60		
HAD-D	39	4.50	3.41	0.57	0.01
EF	39	23.61	10.60		

**Table 23: Pearson correlations of partner distress scores with emotion focused coping.**

Again from this table, it can be seen that the correlation between HAD-D and emotion focused coping is stronger for partners than the correlations for HAD-A.

As the research indicates an inconsistent relationship between problem focused coping and distress, further analysis was conducted to assess the association between problem focused coping and HAD-A and HAD-D. A two tailed level of significance was employed. As table 24 indicates, no significant associations were found for problem focused coping and levels of distress. However, for HAD-D (partners) there is an inverse non significant relationship suggests that greater levels of PF coping is related to lower levels of distress. Overall, the findings suggest that no relationship exists with either HAD-A and HAD-D and PF coping for either patient or partner.

	Patients =42		Partners=39	
Measures	R	Sig (2 tailed)	r	Sig (2 tailed)
HAD-A	0.05	0.36	0.10	0.27
HAD-D	0.10	0.26	-0.20	0.11

**Table 24: Correlations between problem focused coping and distress measures for patients and partners.**

### Summary

The hypothesis that emotion focused coping would be positively correlated with distress was confirmed for both patient and partner. The correlations for HAD-D and emotion focused coping were higher in both cases. Further analysis examined the relationship between problem focused coping and HAD-A and HAD-D and no significant associations were found. This is contrary to many past research findings. Further analysis of the predictive value of emotion focused coping with other variables associated with HAD-A and HAD-D will be investigated later using multivariate analyses (see section 3.4).



### 3.3.6 Hypothesis six: Greater discrepancies in problem focused coping in couples will be related to lower levels of anxiety and depression in patients and partners.

In line with Pakenham (1998) this hypothesis predicted that there would be an association between greater differences in problem focused coping in couples and lower levels of distress. To assess the difference in PF coping, patients and their corresponding partners PF coping scores were examined, and a new variable 'PF coping discrepancy' was created. This represents the difference between patients and partners scores on the PF scale. The mean difference in PF coping between patients and partners was 12.74 (SD = 9.52).

A Pearson's correlation was conducted between 'PF coping discrepancy' (PFDIS) and HAD-A and HAD-D for patients. As tables 25 and 26 illustrate, significant correlations were not found between HAD-A and PFDIS or HAD-D and PFDIS, although the correlation between discrepancy in problem focused coping and HAD-D was approaching significance ( $r=0.23$ ,  $p=0.08$ ).

	N	M	SD	r	Sig (1 tailed)
<b>HAD-A</b>	42	7.59	3.92	0.09	0.30
<b>PFDIS</b>	39	12.74	9.52		

**Table 25: Discrepancy in couple PF coping and HAD-A for patients.**

	N	M	SD	r	Sig (1 tailed)
<b>HAD D</b>	42	6.71	3.65	0.23	0.08
<b>PFDIS</b>	39	12.74	9.52		

**Table 26: Discrepancy in couple PF coping and HAD-D for patients.**

### Partner distress and PF coping difference

A similar analysis was conducted for PF coping discrepancy and partners distress scores. A significant relationship was not found between discrepancy in couple PF score and HAD-D or HAD-A as illustrated in tables 27 and 28, below.

	N	M	SD	r	Sig (1 tailed)
<b>HAD-A</b>	39	6.85	3.87	0.20	0.11
<b>PFDIS</b>	39	12.74	9.52		

**Table 27: Discrepancy in couple PF coping and HAD-A for partners.**

	N	M	SD	r	Sig (1 tailed)
<b>HAD D</b>	39	4.50	3.41	0.13	0.21
<b>PFDIS</b>	39	12.74	9.52		

**Table 28: Discrepancy in couple PF coping and HAD-D for partners.**

### Summary

The results of this analysis suggests that the difference between patient and partner problem focused coping is not associated with lower levels of either HAD-A or HAD-D in patients or partners. This hypothesis is therefore not confirmed.

**3.3.7. Hypothesis seven: Greater dissatisfaction with emotional and practical social support in patients and partners will be related to greater distress as assessed by the HAD.**

This hypothesis was tested principally using Pearson correlations between measures of social support (SOS-B), anxiety (HAD-A) and depression (HAD-D). Analyses were carried out for patients and partners separately. The relationship between social support and levels of distress in patients is illustrated in table 29.

Patients N=42	Discrepancies in emotional support		Discrepancies in practical support	
	r	Sig (1 tailed)	r	Sig (1 tailed)
HAD-A	0.11	0.10	0.08	0.29
HAD-D	0.36	0.01	0.30	0.03

**Table 29: Relationship between dissatisfaction in emotional and practical support and distress in patients.**

For the patient group it can be seen that the relationship between dissatisfaction in support reaches significance for both emotional ( $r=0.36$ ,  $p<0.01$ ) and practical support ( $r=0.30$ ,  $p<0.03$ ) for HAD-D. However, no relationship was found between HAD-A and dissatisfaction in emotional support and dissatisfaction in practical support. A similar analysis was conducted for partners, as indicated in table 30 below:

Partners	Discrepancies in emotional support		Discrepancies in practical support	
	r	Sig (1 tailed)	R	Sig (1 tailed)
HAD-A	0.30	0.03	0.16	0.15
HAD-D	0.32	0.02	0.29	0.04

**Table 30: Relationship between dissatisfaction in emotional and practical support and distress in partners.**

Table 30, above indicates that HAD-A is associated with dissatisfaction in emotional support ( $r=0.30$ ,  $p<0.03$ ) but not practical support, and HAD-D is associated with both higher dissatisfaction in emotional support ( $r=0.32$ ,  $p<0.02$ ) and practical support ( $r=0.29$ ,  $p<0.04$ ). Overall, these results provide support for the hypothesis that dissatisfaction in support (both emotional and practical) are related to higher levels of distress in partners. Multivariate analysis will be conducted later (see section 3.4 ) to assess the contribution of dissatisfaction in support along with the other variables found to be associated with distress.

Further analysis was conducted to assess the differences between patients and partner on the support measures. Table 31, below illustrates patients and partners means, standard deviations and the difference between groups on actual emotional support (AES), ideal emotional support (IES), discrepancy in emotional support (DISES), actual practical support (APS), ideal practical support (IPS) and discrepancy in practical support (DISPS).

	PATIENT N=42		PARTNER N=39			
	Mean	SD	Mean	SD	t	Sig(2tailed)
<b>AES</b>	5.38	0.81	5.42	0.95	-0.24	0.80
<b>IES</b>	5.84	0.82	6.07	0.63	-1.39	0.16
<b>DISES</b>	0.47	0.48	0.70	0.77	1.64	0.10
<b>APS</b>	4.91	1.02	4.89	0.95	0.08	0.92
<b>IPS</b>	5.41	0.92	5.69	0.82	-1.46	0.15
<b>DISPS</b>	0.52	0.53	0.80	0.74	-1.99	0.05

**Table 31: Independent t tests for patients and partners on the subscales of the SOS (B).**

Both patient and partners actual and ideal mean perception of levels of support were around the 'sometimes' to 'always' (4-6) level of the scale suggesting they are fairly satisfied with the support received. To assess if statistically significant differences existed between patient and partners perception of support, independent t tests were conducted as illustrated in table 31 above. A significant difference was found only for discrepancy in practical support ( $t = -1.99, p < 0.05$ ), suggesting that partners are less satisfied with practical support than patients.

Further analysis was conducted on patient's and partners assessment of the support they received from each other. As the spouse is often the main provider of both emotional and practical support, it was considered important to assess how patients and partners perceived the level of support received from each other. A 2 tailed level of significance was used.

	Patient		Partner		t	Sig (2 tailed)
	M	SD	M	SD		
<b>Esa</b>	6.28	1.05	5.95	1.13	1.39	0.16
<b>Esideal</b>	6.84	0.34	6.67	0.46	1.87	0.06
<b>Esdis</b>	0.54	0.94	0.72	1.10	-0.79	0.43
<b>Psa</b>	6.22	1.07	5.15	1.38	3.95	0.01
<b>Psideal</b>	6.73	0.50	6.30	0.77	3.00	0.01
<b>Pdis</b>	0.51	0.81	1.16	1.27	-2.80	0.01

**Table 32: Between group differences for patients and partners on the subscales of the SOS (B).**

Table 32 indicates significant differences between patients and partners for actual practical support, ideal practical support and discrepancy in practical support. Patients perceive they are receiving significantly higher levels of practical support, ( $t = 3.95, p < 0.01$ ) and have a higher ideal for the support they should receive ( $t = 3.00, p < 0.01$ ). In line with the analysis in table 31 above, partners are significantly more dissatisfied

with the practical support they receive from the patient ( $t=-2.80$ ,  $p<0.01$ ). However, despite this it is important to note that partners appraisal of the patients emotional and practical support lies between 5-6 in the scale, which as noted above indicates a good degree of satisfaction.

### **Summary**

In summary it appears that there is some support that dissatisfaction with social support is linked with higher levels of distress. The strongest relationship appears to be with the HAD depression measure for both patients and partners for both discrepancy in emotional and practical support. However, HAD A correlates with discrepancy in emotional support only for partners. Therefore, jointly, the data for patients and partners provides evidence to support the hypothesis that dissatisfaction with support will be related to poorer mental health. It is interesting, but not surprising to note that partners are more dissatisfied than patients with the amount of practical support they receive.

### **3.4.0 MULTIPLE REGRESSION ANALYSIS**

Variables that indicated association at the 0.05 level of association or below with patient or partners on measures of distress were selected for inclusion in regression and multiple regression analysis. The purpose of this analysis was to assess the contribution of these variables to levels of psychological distress.

#### **(a) PATIENT ANALYSIS**

##### **Criterion variable: HAD-D**

The following variables, emotion focused coping (EF), discrepancy in emotional support (Esdís) and discrepancy in practical support (Psdis) were found to be significantly correlated with HAD-D and were entered in a stepwise procedure to the regression equation. The regression equation for HAD-D is shown in table 33.

Criterion Variable	Variables in the equation	Final beta	t	Sig
HAD-D	EF	0.507	3.932	0.0001
	Esdís	0.283	2.195	0.03
<i>R<sup>2</sup>=0.401</i>				
<i>Adjusted R<sup>2</sup>=0.369</i>				
<b>Predictor variable removed from the model</b>				
	Psdís	0.080	0.475	0.637

**Table 33: Stepwise multiple regression of predictor variables with the criterion variable, HAD-D for patients.**

It can be seen from table 33 that emotion focused coping and discrepancy in emotional support together predict the greatest proportion of the variance (37%) (Adjusted  $R^2=0.369$ ), although the higher beta for emotion focused coping would suggest that this is the most important variable in the model. Discrepancy in practical social



support was excluded as it added little to the equation. Therefore this equation suggests that with regard to distress in patients (as assessed by HAD-D), emotion focused coping and discrepancy in emotional support are the strongest predictors.

#### (b) PARTNER ANALYSIS

As noted above the variables that correlated significantly with partner distress scores were entered into regression equations.

##### Criterion variable: HAD-A

The following independent variables were entered; EF and Es dis. Table 34 illustrates the result of this regression.

Criterion Variable	Variables in the equation	Final beta	t	Sig
HAD-A	EF	0.383	2.491	0.02
<i>R<sup>2</sup>=0.147</i>				
<i>Adjusted R<sup>2</sup>=0.123</i>				
Predictor variable removed from the model				
	Esdis	0.178	1.01	0.316

**Table 34: Stepwise multiple regression of predictor variables for HAD A in partners.**

Table 34 illustrates that emotion focused coping was the only predictive variable, accounting for 12 % of the variance in HAD-A (Adjusted  $R^2 = 0.123$ ,  $p=0.02$ ). Discrepancy in emotional support (Ef dis) was excluded from this equation, and did not contribute a significant proportion of the variance.

### Criterion variable: HAD-D

The variables that were associated with HAD-D were entered into the regression equation, namely emotion focused coping, dissatisfaction in emotion and practical support and the disability measure (Barthell index).

Table 35, below illustrates the results of this regression.

Criterion Variable	Variables in the equation	Final beta	t	Sig
HAD-D	EF	0.576	4.231	0.0001
$R^2 = 0.332$				
$Adjusted R^2 = 0.314$				
Predictor variables excluded from the model				
	Barthell	-0.229	1.673	0.103
	Esdis	0.050	0.320	0.751
	Psdis	0.009	0.056	0.955

**Table 35: Stepwise multiple regression of predictor variables and criterion variable, HAD D for partners.**

From table 35 above, it can be seen that on its own emotion focused coping explains 31% of the variance in HAD-D ( $Adjusted R^2=0.314$ ,  $p<0.0001$ ). The other variables were excluded as they did not appear to be explaining a significant proportion of the variance.

#### 3.4.1 Summary of Multiple Regressions

From the above multiple regressions it can be seen that emotion focused coping is the most important predictors in both patient and partner analysis. Other important variables that emerged were discrepancy in emotional support for patients. These findings will be discussed further in the discussion.

### **3.5.0 Thematic Analysis of Qualitative data**

The qualitative data derived from the semi-structured interview was assessed for themes. The identification of themes was guided by the researchers interpretation and understanding of the individual responses given by both patient and partner. The following analysis will be presented in different sections pertaining to the questions asked at interview, with specific reference made to their relevance to the experimental hypotheses.

The data is presented in the form of quotes which are to the right of the bullet points, as well as text which provides more detail about some of the comments.

#### **Effects of the illness**

##### **Negative effects**

##### ***Loss of independence/restriction***

This appeared to be a central theme running throughout most interviews with patients. The fact that they were no longer independent, and had to depend on others to help organise their life was deeply troubling. The following comments were representative of the feelings of many patients:

- "I miss my independence, and don't like relying on my partner. I can no longer be spontaneous".
- "I am unable to pursue any of my hobbies anymore, particularly sports. Life can be very boring".
- "I miss playing outside with my children".
- "I hate being cared for, and find other people coping with my incontinence totally degrading."
- "If I need to go somewhere, even to the shop, I have to ask for help. Asking for help is the worst part of it, I feel I am imposing on other people's time".

### **Negative effects: partners**

#### ***Feeling restricted/giving up roles and activities***

Again, for partners feeling restricted was the main negative effect, and was discussed by the majority of partners.

- "I have no free time to go away, even for a day, being confined gets me down".
- "Having to give up work, I really miss work, sometimes feel I have MS too".
- "I feel caged, and that I have no purpose".

#### **Positive effects associated with the illness**

Many individuals (patients and partners alike) initially found this a difficult question to answer. In fact many could see no positive effect of the illness at all. However, after some thought the following responses were provided:

### **Patients**

- "I have more time for hobbies and can see more of my family".
- "I am more aware of people with different disabilities, have more understanding".
- "It has made me more tolerant, more easygoing".
- "It has made me a lot stronger, and have brought children up to be more caring and respectful of people with disabilities".

Interestingly many patients stated that being disabled had changed their attitude to other disabled people.

## **Partners**

Partners spoke about the importance of their role as caregiver, and the closeness they now shared with the patient. The comments represented below suggest that partners felt that providing the best care was important, and gave them a sense of satisfaction.

- "Knowing that I am helping her, gives me a sense of satisfaction".
- "Feel it's an important role, that I am needed".
- "I have become a more caring person, and am more tolerant".
- "Knowing that she's getting the best care".
- "I know it if was me she would do the same".
- "Its has brought us closer together, and makes me appreciate the time we have together".

## **Relationship satisfaction**

A five point likert scale was used to assess the degree of relationship satisfaction of both patients and partners. For both groups, there appeared to be a high level of marital satisfaction with the majority of patients and partners alike rating themselves between moderately to very happy with their relationships. At interviews, many participants spoke about the importance of the marital relationship and noted that this had changed very little since developing MS. However, as this sample had been married for a considerably long time, and in many cases had been diagnosed many years before, caution is warranted before this is generalised to other couples where one has MS, particularly younger couples.

### **Coping in general with MS**

In response to the question about what they do to cope with their illness, patients and partners spoke of the practical and emotional strategies they use. With regard to problem focused coping, making plans and getting outside help appeared to feature in many people's responses.

#### **Problem focused coping**

- "Organising a home help to clean the house was a big help".
- "When I was first diagnosed, making plans for the future. We moved to a bungalow just in case the MS got much worse".
- "The rehab team have been great, and have provided me with many ideas to make my life easier".
- "Medication has helped, talking to people".
- "Breaking tasks down, not expecting too much of myself".

Practical strategies mentioned were those used to minimise the effects of the disability for example getting adaptations made to their homes, and using walking aids including wheelchairs. However, some patients expressed ambiguity over the use of walking aids and wheelchairs. On the one hand, some believed that the use of a wheelchair or walking aid provided them with more independence, therefore minimising the physical restriction. On the other hand, wheelchairs were perceived as very much a symbol of disability, and patients expressed reluctance to use them, both due to the perception that they were 'giving in' to the illness, as well as how other people would react to them.

### **Emotion focused strategies**

Emotion focused strategies used by patients and partners were very similar, and on the whole suggested that little time was spent thinking about or discussing MS. The main strategies discussed are presented below:

- "I just take one day at a time".
- "Live for now, don't live for what you what you once were".
- "Don't think about the future".
- "I don't talk or think much about it, just get on with it".
- "I don't regret what I can't do, if you do, you get down".
- "I don't think about it anymore, I've got it, just live with it".
- "I shout a lot and get angry about things I can't do. Its very frustrating".
- "I try to keep my spirit up- I never wallow".

With follow up questioning, it appeared that many couples did not plan too far ahead, and instead kept, what has been referred to in the literature as a 'present focus'. Although the 'Revised Ways of Coping Checklist' (RWCC) (Vitaliano *et al*, 1985) has a similar problem focused coping item; 'took things one step at a time', it is arguable whether this is actually a problem focused coping strategy. It was observed that when participants referred to coping by using this strategy, many appeared to be avoiding thinking or planning about the future. One participant commented that thinking too far ahead would be too depressing as he knew that future disability was inevitable. However, for many not thinking about the MS, appeared to be due to the fact that they had been diagnosed for such a long time, that they were accustomed to living with the disability. If conceptualised as avoidance, it is debatable whether or not is beneficial or detrimental to adaptation.

Contrary to this, for some people not planning ahead is detrimental. In the case of people who will have to move home, if this is not considered earlier, then later it may be an even bigger upheaval.



Perhaps one of the most common strategies used, could be described as optimism or hope. Many patients stated that they were waiting for a cure for MS, and were hopeful that one would be found. On the one hand this could be translated as a form of wishful thinking as reflected in the RWCC, which would perhaps be counterindicated for successful adaptation. On the other hand, having this hope of a cure (however unrealistic) was contributing to them feeling better in the present. One participant noted that if they didn't have hope, and instead anticipated the worst, they would not be able to live normally. This reflects the idiosyncrasy of coping and adaption: what was adaptive for some individuals was not adaptive for others.

### **Social support**

Patients and partners discussed the importance of their friends and family, particularly the support that was gained from each other. Interestingly many did not attend support groups such as the MS society, and the most common reason cited for non attendance was the risk of seeing someone very disabled. For many participants seeing very disabled people made them fear that they would have a similar outcome. It could be stated that this is a form of avoidance. Whether or not it is detrimental remains to be seen. The following comments were provided by patients and partners alike.

- "Having people to talk to, especially meeting up with friends".
- "Family being around, especially husband".
- "Wife and family, also work mates have really helped".
- "Getting as much help from outside - medical professionals, Rehab team, talking to someone".
- "Its important not to rely on one person too heavily, I try to maintain contact with my friends, otherwise my husband and I would get on each other's nerves".
- "My wife and I are very close, we support each other".

Subjectively, there appeared a gender divide with regards to reports of social support. In couples where the wife had MS, contact was maintained with friends. However,

when the husband was the disabled partner, he appeared to depend solely on his wife for support, and contact from friends was no longer utilised. An interpretation of this may be that in general women tend to have a larger network size and are able to maintain close relationships with others apart from their partner. Men on the other hand appear to rely solely on the marital relationship for the most support.

### **Other strategies**

The most common other strategy was humour. One MS patient noted that having a sense of humour was important because as they noted 'When I stumble or fall, I don't get embarrassed anymore.....I just comment I'll have to stop drinking'.

### **Couple coping**

Many couples remarked that how they coped with the demands of the illness, very much depended on how their partner coped. In particular, one patient remarked that due to her partner's foresight and planning she was able to deal with the demands of the illness better. Her partner had adapted the house when the patient was only mildly disabled and continually searched for ways of minimising her disability. Interestingly, these adaptations were unobtrusive, i.e. instead of a disabled cup, he would purchase a 'normal cup' with large handles. Similarly, partners often noted that they could not have coped if the patients had not coped so well. For example, one partner noted 'She never lets it get her down, she's so bright and cheery, I think if she was to wallow in it, I wouldn't be able to cope'. This was an interesting comment, as it suggests that the partner may not be able to talk about the illness, and may discourage his wife to do so. While this is conducive to his emotional well being, it may be frustrating for his wife.

### **Summary**

The above analysis suggests that the main effects of MS appears to be loss of independence for both patients and partner's alike. Interestingly some positive effects were found, and these were mainly concerned with being able to spend more time with friends and family (patients) and the importance of providing the best care for the

patient (partners). Relationship satisfaction appeared to be high for both patients and partners, and participants perceived little change in their relationship since MS was diagnosed.

A wide range of coping efforts were used by both, although there was a sense that coping had become automatic for these couples, as reflected by the remarks that they 'just get on with it'. Although many patients were very disabled, they appeared to cope with maintaining a present focus rather than thinking too much about the future.

## **4.0 DISCUSSION**

### **4.1.0 Summary of results**

Overall, this sample did not appear to be significantly distressed as assessed by their mean scores which fell into the normal range for HAD anxiety and depression scales, and just above caseness for the GHQ 28 for patients. Examining the data in terms of caseness and cut off points, over a third of the sample of patients and between 15 to 43 per cent of their spouses reported mild to moderate levels of distress with a few reporting severe mental health difficulties.

The results from this study suggest, as expected patients are more distressed than partners, particularly on measures which assess symptoms of depression (HAD D and GHQ 'severe depression') and a measure of strain (CSI). Although partners experienced less distress, there was evidence to suggest that a proportion of partners were at least mildly anxious and depressed. In addition, findings suggest that patients and partners distress was correlated for HAD depression, but not for HAD anxiety or GHQ 28 or CSI.

There was no association between distress and level of disability and length of diagnosis for patients. However, for partners, patient's level of disability was associated with distress (HAD D), suggesting that the more disabled the patient the more distressed the partner.

With regard to coping, emotion focused coping was the most significant predictor of both patient and partner distress. The discrepancy in problem focused coping between couples was not associated with patient or partner distress.

Dissatisfaction in emotional social support was significantly associated with measures of distress, and emerged as a significant predictor of distress in the regression analysis for patients.

It could be stated that, with regard to distress, the patient sample does not appear significantly distressed, and as such does not fit the notion that a significant number of patients with MS are distressed (McIvor *et al.* 1984). However, some studies have found levels of distress to be low. For example, Dalos *et.al* (1983) found mean scores on the GHQ similar to the present sample in his sample of MS patients with a progressive course.

It is difficult to judge whether partner carers in this sample reflect past research as few studies have used anxiety or depression questionnaires. However, one study (O'Brien, *et al.* 1995) found spousal caregivers to have mean GHQ 28 scores in the normal range, which is comparable to the present study. It could be tentatively concluded that the present sample of partners are not unlike a normal population.

#### 4.2.1 Hypothesis one

Predictably, the results suggest patients report greater levels of psychological distress as evidenced by significantly greater levels of distress in HAD anxiety, HAD depression, GHQ 28 and CSI. Further analysis revealed that patients had significantly higher scores on the GHQ 28 subscales 'social dysfunction', perhaps suggesting a greater difficulty carrying out their normal day to day activities as well as 'severe depression' which is consistent with differences found also for the HAD D.

The finding that patients are more distressed than their carers on anxiety and depression and are more strained by the demands of the illness is consistent with Pakenham (1998), although his sample comprised of partner carers and relatives of persons with MS. Research that has examined couples in other chronic illnesses would support this finding (Soskolne & De Nour, 1989; Walsh *et al*, 1999). The differences between patients and partners on the strain index (CSI) in the present study is interesting, but not surprising, suggesting that the strain felt by the illness is significantly greater for patients. While one may be tempted to conclude that the differences found are due to the social and emotional consequences of the illness on the patient, this may not be the case. Instead, several possibilities exist with regard to this finding. It is possible that the finding is a result of the greater proportion of female patients in the present sample, and may be due to a reporting bias with females more likely to admit to the symptoms of distress than males. (Nolen-Hoeksema, 1987). However, one of the hypotheses tested for this possibility and found that no differences existed in gender on measures of distress for either patients or partners.

Another possibility that was discussed earlier, is the potential confounding of the symptoms of distress with MS symptoms. Although the measures chosen aimed to limit this, it is possible that self report measures may not be the most reliable method for measuring distress in this group. Instead, it may be advisable to assess patients at interview to limit the endorsement of responses associated with MS, and to assess whether or not cognitive impairment is present. With regard to hypothesis one, it

could be tentatively concluded that patients reported higher levels of distress than partners, and it would seem reasonable to assume that this was due to the emotional and social effects of the illness.

#### **4.2.2 Hypothesis two**

It was predicted that patients and partners distress would be correlated. For the whole sample this hypothesis was partly confirmed, as indicated by the positive correlation between patients and partners on the HAD depression scale. However, when patients who were distressed (as assessed by cut-offs in measures of distress) were correlated with their partners, this relationship, although not significant, was heading in the expected direction. The finding that patients and partners distress is associated is consistent with research in couple's where one has a chronic illness (Pakenham, 1998; Soskolne & De Nour, 1989; Walsh *et al.*, 1999) as well as research which has examined depressed patients and their partners (Coyne *et al.*, 1987). As noted by Coyne *et al.*, (1987) living with a distressed person may be upsetting for the partner, particularly in terms of the effects of low mood, withdrawal and lack of interest. In terms of the interactional model of depression, a negative reaction from others has been cited as having a key role in the development and maintenance of symptoms (Coyne, 1987).

The correlational design of the present study makes it difficult to assess in what way distress is associated. Questions that arise from this finding are: who is distressed first, the patient or the partner, or does no consistent pattern appear. It is beyond the present study to answer this question and it is possible that a longitudinal study which assesses distress at different time points may be able to clarify this further. Further elucidation of how distress is transmitted may suggest ways of intervening both with the individual or at the couple level.

It is important to note that distress was not correlated for either HAD anxiety or the GHQ total. It is important not to speculate too much about this finding, particularly

because the correlation of HAD-D in patients and partners was fairly modest ( $r=0.40$ ,  $p<0.05$ ).

#### **4.2.3 Hypotheses three and four**

##### **The influence of years diagnosed and disability**

The number of years patients had been diagnosed and their level of disability was not found to be related to distress in the bivariate analysis for patient. These findings are in line with previous research (Maybury & Brewin, 1984; Minden & Schiffer, 1990; Zeldow & Pavlou 1984). It is possible that the lack of significant associations between distress and illness related variables for patients is due to the characteristics of the present sample. The patients in the present sample had been diagnosed for a considerable length of time and were moderately to severely disabled, and on the whole not significantly distressed. It is possible that patients had generally adapted to living with the disease. Evidence for this comes from comments made by patients in the semi-structured interviews; many patients who had been diagnosed upwards of 15 years stated that they had become accustomed to the symptoms of MS, and had accepted it. Alternatively, patients may be particularly adept at using emotion focused coping such as avoidance and avoid thinking or discussing the illness. Subjectively this was borne out by the comments in the semi-structured interviews.

Although a significant relationship was not found between years diagnosed and distress for partners, a significant relationship was found between partners distress (as assessed by the HAD-D) and greater disability in the patient. This is not consistent with findings by O'Brien, *et al.* (1995) who found that disability in the patient was not associated with greater distress in the partner. Distress in partners who are living with a more disabled partner may operate in one of two ways. On the one hand, partners who are living with a patient who is more greatly disabled may have to provide practical help, and it is possible that time is compromised to pursue other activities that would sustain their well being. This finding is supported by studies which have



found that caregivers who spend considerable amount of time helping with activities of daily living experience more distress (Vitaliano, Russo, Young, Becker & Maiuro, 1991). An alternative explanation is that distress is due to the effect of witnessing a spouse who was previously well become very disabled. However, findings from the thematic analysis would favour the former interpretation; for many partners the most frustrating aspect of MS was the activities they had to give up, particularly work and leisure pursuits.

### **Gender and age**

Significant differences did not emerge between males and females (patients and partners) for distress in either HAD anxiety or HAD depression or the GHQ 28. Mean scores were higher for females (patients and partners) on the HAD scales, whereas there was a trend for males to score higher on the GHQ 28. Similarly, there was no association found between age and distress. There has been little research on the effects of age or gender in either MS patients or MS caregivers. However, the finding that gender and age were not associated with distress is consistent with a study by Knight *et al* (1997). Similarly, Zeldow & Pavlou (1984) found that gender was not a significant predictor of distress in their sample of MS patients. Nevertheless, the finding that no gender effects emerged, is contrary to broader research findings (Nolen-Hoeksema, 1987), which suggest that women tend to report significantly greater levels of distress than men. While, it is possible that there are no gender or age differences in distress in MS patients and partners, it is not possible to conclude this at present; the potential influence of demographic variables such as gender and age should be further explored in future research.

### **4.2.5 Hypothesis five**

The hypothesis that greater levels of emotion focused coping would be linked to greater levels of distress was confirmed for both patients and partners and it was the most important predictor of distress in the regression analysis. This finding is consistent with the general literature on stress and coping (Folkman *et al.* 1986) and

studies that have been conducted with MS patients (Pakenham, 1998; Jean *et al.* 1999), MS spousal caregivers (O'Brien, 1993; Pakenham, 1998), as well as the multitude of studies that have been conducted with both patients with chronic illness (Revenson & Felton, 1989) and those caring for them (Wright *et al.* 1991). Emotion focused coping therefore appears to be an important mediator of distress in both groups, and in this sample its association with distress suggests it is not conducive to well being in either patients or partners.

#### **4.2.6 Hypothesis six**

It was predicted that with regard to couple coping, greater differences in problem focused coping would be related to lower levels of distress in both patients and partners. This hypothesis was not confirmed and therefore does not support the findings from Pakenham (1998) in his sample of MS patients and their caregivers. It is possible that this finding may be due to a problem in the method used to assess couple coping by both Pakenham (1998) and Ptacek & Dodge (1995), and consequently the present study.

Calculating the difference between partner's scores is perhaps a crude way of assessing the impact of the dyad's coping on distress. It could be argued that this method is not sensitive to the level of coping each partner is using. More specifically, this method does not allow us to determine where the discrepancy lies between partners. It is possible that one partner may be using a high degree of problem focused coping and the patient a low level of problem focused coping. Similarly, in another couple it could be the patient who is using the high level, and the partner the low level. Determining which partner uses which type of coping may be more important than assessing the differences between them.

An alternative method to assess couple coping is to cross correlate patient and partner coping with their respective levels of distress. Using this method some studies have found significant relationships between patients distress and partners coping and vice

versa (Coyne & Smith, 1991; Ey *et al.* 1998). As so few studies have been conducted on couple coping it is not clear if the finding from the present study is due to a problem with assessment of couple coping. Further research should be conducted to assess if this method of assessing couple coping is viable.

The potential difficulties in assessing couple coping through measurement scales has been highlighted above. It is possible that coping questionnaires may not be a sensitive enough method of assessing how couple's cope. Qualitative assessment is one potential way of gaining valuable information about how couple's cope. In the present study, comments noted by patients and their partners provided some very useful insights into how couple coping operates. For example, many partners remarked that they would not have coped so well without the support and coping of the patient. Interestingly, when questioned further it appeared that coping often meant that the patients 'got on with it' and did not 'complain' about their symptoms, thus not expressing their feelings to their partner. Arguably this type of coping could be described as a form of emotion focused coping such as avoidance. While this may be beneficial for the partner, it may not be conducive to the patient's well being. This example also highlights the issue of perception, it appears that one's perception of how another is coping may be an important mediator of distress, even if that perception is misguided.

With regard to couple problem focused coping, the account provided by one couple suggested that the husband (non MS sufferer) was very much a problem focused copier, and planner. He had, by his own and his wife's account made plans very early on in her illness, and had made many adaptations to their home. His reasoning was that it was important to prepare for the worst, and if the worst (severe disability) was to occur then at least all his efforts would make his wife more comfortable. Interestingly, in this couple the husband appeared distressed whereas his wife was not. This perhaps suggests that one member may cope on behalf of the other, and in this example it would appear that this was beneficial for the wife, but not the husband. It

is possible that gender has a role to play in couple coping, and as suggested earlier men have often been found to be more problem focused copers (Barusch & Spaid, 1989), whereas women may use more emotion focused coping. It would be interesting to assess how gender operates in couple's coping, and this would provide an avenue for future research.

#### **4.2.7 Hypothesis seven**

The hypothesis that greater dissatisfaction in emotional and practical support would be related to higher levels of distress in patients and partners was confirmed.

Interestingly, patients and partners mean levels of both practical and emotional social support were quite high (between 4-6 on the SOS-B). Similarly, the mean discrepancies between emotional support and practical support were low indicating a certain degree of satisfaction with both emotional and practical support.

Although the hypothesis was confirmed at the bivariate level for both patients and partners, only dissatisfaction in emotional support was predictive of distress for patients in a multiple regression equation. Overall, these findings are consistent with previous research which suggests that perception or satisfaction with support is one of the key determinants of well being (Swindells *et al* 1999).

The association between distress and dissatisfaction with emotional and practical support is perhaps not surprising for patients or partners, particularly since many of the patients in the present sample were characterised as moderately to severely disabled. As a result of disability, it is likely that patients have reduced opportunity for gaining support (Wineman, 1990). Similarly, partners may have increased caregiving tasks, that would prevent them from maintaining important social contacts. The research literature suggest that the structural components of support (availability of social relationships) are essential for one's well being.

Further analysis suggested that partners were more dissatisfied than patients with the practical support they received. Not surprisingly this finding held when patients and partner's perception of support they received from each other was assessed. The finding that partners are more dissatisfied with practical support is important and suggests that partners may require more practical assistance. In long term intimate relationships, it is often the spouse who provides both practical and emotional support, and perhaps with the impact of MS, this support is no longer available. It has been noted that in chronic illnesses, the spouse (person without MS) is often neglected as the focus is often on the person with the illness (Murray, 1995). It is possible that this group of partners are not gaining enough support outside of the marital relationship. As noted above this is an important finding, however caution is required in suggesting that more practical and emotional support is required. In future research, it would be useful to explore qualitatively the aspects of support that provide the most dissatisfaction, and also to assess what the patient and partner would recommend to decrease this dissatisfaction.

Furthermore, this study did not assess what formal support was available to couples, although it is debatable whether or not formal support is important in maintaining well being (Gilhooly *et al.* 1994). During the semi-structured interviews, many patients and partners expressed a reluctance to attend support groups such as the MS society. This reluctance appeared to be associated with the distress of seeing other MS sufferers who were more disabled, and the corresponding thought that that this level of disability would eventually come to them. This is an interesting finding and may apply to other support groups for individuals with other long term deteriorating conditions.

Although this hypothesis was confirmed, it is important to add that the correlational design of the present study makes it difficult to conclude if dissatisfaction causes distress or vice versa.

#### **4.3.0 Practical implications of research**

The principal objective of the present study was to examine factors highlighted in the literature associated with distress in both MS patient and partner. The findings that emerged suggest that, emotion focused coping and discrepancy in emotional support were the strongest predictors of distress.

It is questionable whether the present sample as a whole could be considered distressed enough to warrant some form of intervention. However, a minority of both patients and partners were moderately distressed. Although, the research literature has long established that MS patients are at risk for experiencing psychological distress, there is little evidence of interventions specifically tailored to their needs. Interestingly, Vanderplate (1984) suggests that traditional psychotherapy may not be the most beneficial approach for this client group and suggests, that time should be spent focusing on adaptive issues as well as aiming to facilitate positive coping. Perhaps one of the most difficult challenges for the MS patient and partner, is the knowledge that the condition is progressive, and that at present no cure is available. The unpredictable and progressive nature suggest that some form of intervention may be necessary at different times in a couple's life.

It is arguable whether individual therapy or joint therapy is advisable, but there is an argument that providing some form of advice about coping and social support may prevent couple's maintaining distress. Kotchick, Forehand, Armistead, Klein & Weirson (1996) note that families should be made aware of the adverse effects of using avoidant coping strategies, such as denial, alcohol, drugs or avoidant thinking. Instead, education should focus on teaching which coping strategy increases distress, and how maladaptive coping can affect other family members, what they term the 'ripple' effect of coping on others. Although this advice is primarily directed toward families, it is particularly relevant to couples, arguably older couples, where the marriage has become the most important relationship.



Although the greatest majority of couples were recruited from an outpatient rehabilitation service, input from clinical psychology is limited. Families are primarily supported by a rehabilitation nurse and other team members. The findings suggest that further input from clinical psychology could be beneficial, particularly ongoing input that allows couples to be seen when disability progresses from a relapsing/remitting course to a secondary progressive course. The finding that partners who live with a more disabled patient are more distressed would suggest that psychological input, combined with more practical support may be beneficial.

A literature search could find no evidence of psychological interventions aimed at couples where one partner had MS. Researchers in other illness areas have suggested that joint therapy is more effective than supporting either the patient or the partner separately (Flor, Turk & Rudy 1987). Murray (1995) recommends that the caregiving partner attends the clinic with the patient and is involved in the discussions, as well as both members attending separate educational workshops and self-help groups. Although Murray (1995) notes that they have organised these interventions for couples, unfortunately they did not report on their outcome.

A recent meta-analysis that assessed the efficacy of treatment for depression in MS was conducted by Mohr & Goodkin (1999). These studies suggested that psychotherapy and antidepressant medication were very effective, but unlike other studies where patients who had not received treatment (i.e. waiting list control) had improved over time, MS patients appeared more likely to become depressed over time without any intervention. This differs from studies in other psychiatric outpatients where some improvement in depression occurs even in the absence of treatment. In addition, Mohr & Goodkin (1999) highlighted that some psychotherapies were more effective than others; psychotherapies that focus on developing coping skills were significantly more effective than insight-orientated therapy for MS patients. This perhaps reflects the fact that MS is continually placing new challenges on patients that can overburden existing coping skills. It is important to note the possible limitations

in any therapy or intervention that is dependent on good memory skills, as many MS patients have cognitive dysfunction.

Additionally, Pakenham (1999) notes that interventions for MS patients should be tailored to the individuals needs depending on the principal problem. He notes that with respect to physical problems, the extent to which MS symptoms can be relieved is limited, therefore acceptance of the symptoms may be more adaptive in the long-term than relying on problem solving methods to manage these problems.

In summary, the results from the present study suggest that MS patients and their partners should be considered for interventions, particularly those that facilitate more adaptive coping. It is unclear if treating the patient individually is more effective than treating the partner. Furthermore, interventions or advice provided should highlight the importance of maintaining social contacts, and gaining more support.



#### **4.4.0 Methodological issues**

##### **(a) Strengths of the research**

The current study attempted to address some of the methodological criticisms aimed at past research. It included both demographic and illness related variables that have not been considered in the study of couples coping with MS. While the aim was to extend previous research that has examined mediating factors at the individual level, this study also aimed to examine both patient and partner, at the couple level.

This study aimed to assess a range of people with a diagnosis of MS. The sample was drawn from an outpatient rehabilitation service which did not necessarily take referrals of patients in crisis, and could be viewed as fairly representative of the MS population as a whole. Indeed, many patients were seen from those diagnosed for a couple of years to those who had been diagnosed many years previously.

Coping research has often been criticised for relying on the responses to self report questionnaires of a stressor of recent onset. This study was interested in examining how individuals coped with a life long stressor- chronic illness, and because it was referring to a specific stressor over a longer time frame, it allowed assessment of couples coping responses. Furthermore the present study gained data from an additional source; qualitative responses to semi-structured interview, from both patient and partner.

Lastly, the present study hoped to contribute to an area where there is little research- to assess not only the factors that mediate patient distress, but also factors which moderate distress in the partner.

## **(b) Methodological criticisms of the research**

Criticism could be levelled at the small sample size. Every attempt was made to include all participants suitable for the study. Because the inclusion criteria specified that the partner should be helping the patient in activities of daily living, this limited the sample size. In many cases, patients were primarily helped by other family members or professional carers. Furthermore, many patients who had to be excluded were not in a stable relationship, or had cognitive impairment. Additionally, the study required the participation of both partners and it is possible that may have limited some participants who were working.

Although participation rate was high in those that met the criteria, there may still be a recruitment bias to those couples who are functioning well (Ptacek *et al.* 1995). Therefore, the degree to which this sample represents the population from which it is drawn must be questioned.

Despite attempts to recruit a younger age group of MS patients, there were few participants under the age of 45. While it is likely that this age group is not as disabled as the older group, they may not have identified their partners as carers, even though help was given on activities of daily living. Furthermore, it would have been interesting to assess more fully how their coping responses differed from the older participants.

This study did not include a control group. It would have been useful to find a comparative chronic illness group to use as a matched control. However, some have noted (Vanderplate 1984) that given the unique, ambiguous, unpredictable nature of MS, it is probably not possible to find a comparison group that is truly equivalent on the illness related variables that accompany MS.

The use of a correlational design limits the conclusions that can be drawn, although useful for identifying associations between variables, it does not pinpoint the direction of relationships, nor does it indicate causality. Even where causal relationships do exist, they are likely to be bidirectional (Aldwin & Revenson, 1987). For example, it is not clear whether coping and social support play a causal role in adjustment, or whether they are simply a response to psychological distress (Pakenham *et al.* 1997).

In the present study many patients with MS had eyesight and motor control problems. A pilot study had identified the need to provide cue cards of questionnaire responses to these participants. Nevertheless, variability in presentation may affect the responses given. For example, participants who completed the questionnaires with help may be more inclined to respond in a socially desirable way or may underplay the presence of anxiety or depression. Future research should include a social desirability scale alongside distress and coping measures.

#### **4.5.0 Suggestions for future research**

Future research should focus on conducting longitudinal studies of couples as they progress with the illness. This would provide information that would be useful to couples at different stages of the illness process. Although the present study examined patients who had MS for a long time, it was not possible to assess how their coping at the time of the study reflected their coping in the past. Couple coping should be examined in more detail, as well as the concept of coping congruence, as it is possible that how couples cope may help explain why some couple's adapt better to chronic illness as opposed to others. Additionally, as highlighted throughout this study, research that is conducted with couple's where one partner has MS should take account of the range of factors that may influence distress in both patient and partner. These should include demographic variables such as age and gender, as well as illness related variables such as time since diagnosis, disability in the patient, and the amount of caregiving provided by the partner.

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## **APPENDICES**

Area Rehabilitation Service  
Stirling Royal Infirmary NHS Trust  
Livilands  
Stirling  
FK8 2AU  
(01786) 434000 ext:4366

Dear

I am writing to inform you about a research study I am conducting with people with Multiple Sclerosis and their partners and to enquire if you would be interested in participating.

I am in my third year of a doctoral course in Clinical Psychology at the University of Edinburgh and am currently on placement at the Area Rehabilitation Service, where I understand you are a patient.

For my thesis I am conducting a study which examines the effect of Multiple Sclerosis on both the person with Multiple Sclerosis and their partner. My interest in this area arose from the finding that very little research has been conducted on the effects of Multiple Sclerosis on the individual and only one study has examined both the person with Multiple Sclerosis and their partner. My study is attempting to address this and one of my aims is to investigate the similarities and differences in how each partner deals with Multiple Sclerosis to learn what couples find useful and not so useful.

I enclose a research information sheet that further outlines my study and what the study entails should you both agree to participate. If you agree to participate I anticipate visiting you both at home, or alternatively if you prefer you can come along to the Area Rehabilitation Service at Stirling Royal Infirmary. If work arrangements make daytime appointments difficult, I can arrange to visit in the evening. If you would like further information about the study you can ring me at the number listed above.

I would appreciate it if you could let me know whether or not you are interested in participating by completing the enclosed response sheet. I enclose a stamped addressed envelope for your convenience.

Thank you for your help.

Yours sincerely,

Elaine Carr  
Clinical Psychologist in Training

# RESEARCH INFORMATION SHEET

The relationship of coping and social support to distress in couples where one partner has Multiple Sclerosis.

This study aims to investigate how couples deal with Multiple Sclerosis. While there has been much research looking at couples with other disorders, very little research has been conducted with couples where one person has been diagnosed with MS. Because MS affects a wide range of people at different life stages it would be useful to find out what strategies people use and what they find useful. The information will be invaluable, as it will help us advise others in similar situations, particularly those that have been recently diagnosed.

If you are interested in taking part in this study, I will visit you at home. When we meet I will tell you more about the study and answer any questions you might have.

If you decide to take part, I would like to spend some time asking you and your partner a few questions about what you have found helpful in overcoming some of the challenges you may face as a result of living with Multiple Sclerosis. I will also ask you to fill in a few questionnaires which will ask you how you are feeling, what you do to manage stress and how supported you feel by friends and family. I intend speaking to you and your partner together initially and then separately. This appointment should take approximately one hour and a half.

Your participation in this study is voluntary, and if you decide not to take part it will have no effect on the future care of either your partner or yourself. You will also be free to stop at any time if you are unhappy with any part of the study. If you do decide to take part, with your permission, I will let your GP know by writing to him/her after our meeting.

All information you give me will be treated with the strictest confidence, and will not be shared with anyone. This includes the information given during the separate meetings with you and your partner and neither partner will have access to it. Furthermore, nothing that could identify you will be published in any form. Questionnaires will only be kept for the duration of the research (about 6 months) and will then be destroyed. Once the research is completed, I will let you know how to obtain a summary of the overall results if you wish.

If you have any questions or require more information about the study you may contact me at the number listed below. Your help in this study is greatly appreciated.

Elaine Carr (Clinical Psychologist in Training)  
01786 434000 ext 4366 (Area Rehab Service at Stirling Royal Infirmary)

THANK YOU FOR YOUR HELP

## CONSENT FORM

By signing this consent form, I am consenting to take part in this study, I have read the research information sheet and understand the nature of this study.

I understand that if I am unhappy at any time, I can withdraw my consent. Withdrawing my consent will not affect my treatment in any way.

I understand that the information I give will be treated with the strictest confidence and will not be used for any other purpose.

I \_\_\_\_\_ consent to take part in this study. I give/do not give my permission for my GP to be contacted to inform him/her of my participation.

Signature \_\_\_\_\_

Witnessed by \_\_\_\_\_ (Elaine Carr)

Date \_\_\_\_\_

NAME: .....

DATE: .....

## THE MINI-MENTAL STATE EXAMINATION

### **ORIENTATION**

Score one point for correct answers to each of the following questions:

What is the time? \_\_\_\_\_ date? \_\_\_\_\_ day? \_\_\_\_\_ month? \_\_\_\_\_ year? \_\_\_\_\_ 5 points ( )

(Ask specifically for any parts omitted.)

What is the name of this ward? \_\_\_\_\_ the hospital? \_\_\_\_\_  
the town? \_\_\_\_\_ the district? \_\_\_\_\_ the country? \_\_\_\_\_ 5 points ( )

### **REGISTRATION**

Name 3 objects (one second for each). Score up to 3 points if at the first attempt, the patient repeats the 3 objects you have randomly named. Score 2 or one if this is the number of objects he repeats correctly. Endeavour by further attempts and prompting to have all 3 repeated, so as to test recall later.

3 points ( )

### **ATTENTION AND CALCULATION**

Ask the patient to subtract 7 from 100 and then 7 from the result - repeat this 5 times, scoring one for each time a correct subtraction is performed.

or spell "world" backwards. Score 1 point for each letter in the right position e.g. dlrow = 3 5 points ( )

### **RECALL**

Ask for the 3 objects repeated in the registration test, scoring one for each correctly recalled.

3 points ( )

### **LANGUAGE**

Score one point for 2 objects (a pencil and a watch) correctly named. 2 points ( )

Score one point if the following sentence is correctly repeated first time:  
"No ifs, ands or buts"

1 point ( )

Score 3 if a 3-stage command is correctly executed, score one for each stage; for example "with the index finger of your right hand touch the tip of your nose and then your left ear", or, "take this piece of paper in your right hand, fold it in half, and place it on the floor". 3 points ( )

On a blank piece of paper, write: "close your eyes" and ask the patient to obey what is written. Score one point if he closes his eyes. 1 points ( )

Ask the patient to write a sentence. Score one if the sentence is sensible and has a verb and a subject. 1 points ( )

Draw a pair of intersecting pentagons, each side one inch long. Score one point if this is correctly copied. 1 points ( )

TOTAL SCORE (=30) ( )

From Dick et al. (1984) J. Neurol. Neurosurg. Psychiatr. 47.496.9

The authors suggest that a score of 23 or less is "Suggestive of cognitive impairment". However, this is based on WAIS IQ scores and is therefore likely to be fairly insensitive.

# The Hospital Anxiety and Depression Scale

Name ..... Date .....

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and **underline** the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

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## I feel tense or 'wound up':

Most of the time

A lot of the time

From time to time, occasionally

Not at all

## I still enjoy the things I used to enjoy:

Definitely as much

Not quite so much

Only a little

Hardly at all

## I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly

Yes, but not too badly

A little, but it doesn't worry me

Not at all

(continued overleaf)



# THE HOSPITAL ANXIETY AND DEPRESSION SCALE

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## I can laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

## Worrying thoughts go through my mind:

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

## I feel cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

## I can sit at ease and feel relaxed:

- Definitely
- Usually
- Not often
- Not at all

## I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

## I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all
- Occasionally
- Quite often
- Very often

(continued overleaf)

# THE HOSPITAL ANXIETY AND DEPRESSION SCALE

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# THE GENERAL HEALTH QUESTIONNAIRE

**GHQ 28**

**David Goldberg**

Please read this carefully.

We should like to know if you have had any medical complaints and how your health has been in general, *over the past few weeks*. Please answer **ALL** the questions on the following pages simply by **underlining** the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer **ALL** the questions.

Thank you very much for your co-operation.

## Have you recently

<b>A1 – been feeling perfectly well and in good health?</b>	Better than usual	Same as usual	Worse than usual	Much worse than usual
<b>A2 – been feeling in need of a good tonic?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>A3 – been feeling run down and out of sorts?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>A4 – felt that you are ill?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>A5 – been getting any pains in your head?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>A6 – been getting a feeling of tightness or pressure in your head?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>A7 – been having hot or cold spells?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>B1 – lost much sleep over worry?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>B2 – had difficulty in staying asleep once you are off?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>B3 – felt constantly under strain?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>B4 – been getting edgy and bad-tempered?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>B5 – been getting scared or panicky for no good reason?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>B6 – found everything getting on top of you?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>B7 – been feeling nervous and strung-up all the time?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual

**Please turn over**

Have you recently

<b>C1 – been managing to keep yourself busy and occupied?</b>	More so than usual	Same as usual	Rather less than usual	Much less than usual
<b>C2 – been taking longer over the things you do?</b>	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
<b>C3 – felt on the whole you were doing things well?</b>	Better than usual	About the same	Less well than usual	Much less well
<b>C4 – been satisfied with the way you've carried out your task?</b>	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
<b>C5 – felt that you are playing a useful part in things?</b>	More so than usual	Same as usual	Less useful than usual	Much less useful
<b>C6 – felt capable of making decisions about things?</b>	More so than usual	Same as usual	Less so than usual	Much less capable
<b>C7 – been able to enjoy your normal day-to-day activities?</b>	More so than usual	Same as usual	Less so than usual	Much less than usual

<b>D1 – been thinking of yourself as a worthless person?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>D2 – felt that life is entirely hopeless?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>D3 – felt that life isn't worth living?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>D4 – thought of the possibility that you might make away with yourself?</b>	Definitely not	I don't think so	Has crossed my mind	Definitely have
<b>D5 – found at times you couldn't do anything because your nerves were too bad?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>D6 – found yourself wishing you were dead and away from it all?</b>	Not at all	No more than usual	Rather more than usual	Much more than usual
<b>D7 – found that the idea of taking your own life kept coming into your mind?</b>	Definitely not	I don't think so	Has crossed my mind	Definitely has

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First published 1978

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# SIGNIFICANT OTHERS SCALE (B)



Name: .....

Date: ..... Record Number: .....

## Instructions

Please list below up to seven people who may be important in the individual's life. Typical relationships include partner, mother, father, child, sibling, close friends, plus keyworker. For each person please circle a number from 1 to 7 to show how well he or she provides the type of help that is listed.

The second part of each question asks you to rate how individuals would like things to be if they were exactly as they hoped for. As before, please put a circle around one number between 1 and 7 to show what the rating is.

### Person 1 – .....

Person 1 – .....		Never		Sometimes			Always	
1	a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty? ..	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7

### Person 2 – .....

1	a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty? ..	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7

### Person 3 – .....

1	a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty? ..	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION

**Person 4 –**

	Never		Sometimes			Always	
1 a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7

**Person 5 –**

1 a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7

**Person 6 –**

1 a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7

**Person 7 –**

1 a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
b) What rating would your ideal be?.....	1	2	3	4	5	6	7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION

Power and Champion, 1988. From 'The development of a measure of social support: The Significant Others (SOS) Scale', *British Journal of Clinical Psychology*, 27, 349–58. Reproduced with the kind permission of the authors.

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## Area Rehabilitation Service - Barthel Index

	Date	Date	Date
<b>BOWELS</b>			
0 = Incontinent (or needs to be given suppositories/enemas) 1 = Occasional accident 2 = Continent			
<b>BLADDER</b>			
0 = Incontinent, catheterised. 1 = Occasional accident (max once/24 hour) 2 = Continent			
<b>GROOMING</b>			
0 = Needs help with personal care 1 = Independent face/hair/teeth/shaving (implements provided)			
<b>TOILET USE</b>			
0 = Dependent 1 = Needs some help 2 = Independent (on and off, dressing, wiping)			
<b>FEEDING</b>			
0 = Unable 1 = Needs help cutting, spreading butter etc 2 = Independent (food provided in reach)			
<b>TRANSFER</b>			
0 = Unable – no sitting balance 1 = Major help (1-2 people), can sit 2 = Minor help (verbal or physical), help of one 3 = Independent			
<b>MOBILITY</b>			
0 = Immobile 1 = Wheelchair independent including corners 2 = Walks with help of one person (verbal or physical) with or without use of aid 3 = Independent (may use any aid)			
<b>DRESSING</b>			
0 = Dependent 1 = Needs some help, but can go about unaided. May need some help with zips, buttons etc 2 = Independent			
<b>STAIRS</b>			
0 = Unable 1 = Needs help (verbal, physical, carrying aid) 2 = Independent up and down			
<b>BATHING</b>			
0 = Dependent 1 = Independent			
<b>TOTAL (0-20)</b>			
<b>INTERPRETATION OF SCORE</b>			
0-4     Very Severely Disabled 5-9     Severely Disabled 10-14   Moderately Disabled 15-19   Mildly Disabled 20     Physically independent, but not necessarily normal or socially independent			



## STRAIN INDEX (PATIENT)

The following list includes things that other people found to be difficult living with Multiple Sclerosis. I would like to know if any of these things apply to you. If an item does apply to your situation, would you please indicate **how stressful** you have found it to be by TICKING the appropriate number.

	Not at all  0	A little bit  1	Moderately  2	Quite a bit  3	Extremely  4
Sleep is disturbed					
It is inconvenient (because being helped takes so much time).					
It is a physical strain (because so much effort is required).					
It is confining (because free time is restricted).					
There have been family adjustments (because family routine is disrupted, there is no privacy).					
There have been changes in personal plans (not able to take holidays/ had to turn down or give up a job).					
There have been other demands on my time (having to attend appointments etc.).					
There have been emotional adjustments					
Some symptoms are upsetting (forgetting, incontinence).					
It is upsetting to find I have changed so much from my former self, I feel I am a different person than they I to be.					
There have been work adjustments (because of having to take time off).					
It is a financial strain.					
I am feeling completely overwhelmed (because of worry about my partner, concerns about how to manage).					

## STRAIN INDEX (PARTNER)

The following list includes things that other people found to be difficult in taking care of a partner with Multiple Sclerosis. I would like to know if any of these things apply to you. If an item does apply to your situation, would you please indicate how stressful you have found it to be by TICKING the appropriate number.

	Not at all  0	A little bit  1	Moderately  2	Quite a bit  3	Extremely  4
Sleep is disturbed ( because wife/husband is in and out of bed)					
It is inconvenient (because helping takes so much time).					
It is a physical strain (because so much effort is required).					
It is confining (because free time is restricted).					
There have been family adjustments (because family routine is disrupted, there is no privacy).					
There have been changes in personal plans (not able to take holidays/ had to turn down or give up a job).					
There have been other demands on my time (from other family members, job).					
There have been emotional adjustments (because change in wife/husband's behaviour).					
Some symptoms are upsetting (forgetting, incontinence).					
It is upsetting to find my partner has changed so much from their former self, they are a different person from what they used to be.					
There have been work adjustments (because of having to take time off).					
It is a financial strain.					
I am feeling completely overwhelmed (because of worry about my partner, concerns about how to manage).					

## REVISED WAYS OF COPING CHECKLIST -PATIENT

Please think of how you **generally** cope with the problems associated with MS. The items below represent ways that you may have dealt with these problems. Please place the appropriate number after each statement to indicate the degree to which you used each of the following thoughts/behaviour to deal with your problems.

- 0 = never used
- 1 = rarely used
- 2 = sometimes used
- 3 = regularly used

1. Bargained or compromised to get something positive from the situation
2. Blamed myself
3. Concentrated on something good that could come out of the whole thing
4. Kept my feelings to myself
5. Hoped a miracle would happen.
6. Asked someone I respected for advice and followed it
7. Talked to someone about how I was feeling
8. Stood my ground and fought for what I wanted
9. Refused to believe it had happened
10. Criticised or lectured myself
11. Came up with a couple of different solutions to the problem
12. Wished I was a stronger person -- more optimistic and forceful
13. Accepted my strong feelings, but didn't let them interfere with other things too much
14. Changed something about myself so I could deal with the situation better
15. Accepted sympathy and understanding from someone
16. Got mad at the people or things that caused the problem
17. Slept more than usual
18. Realised I brought the problem on myself
19. Felt bad that I couldn't avoid the problem
20. I knew what had to be done, so I doubled my efforts and tried harder to make things work
21. Daydreamed or imagined a better time or place than the one I was in
22. Tried to forget the whole thing

Please think of how you **generally** cope with the problems associated with MS. The items below represent ways that you may have dealt with these problems. Please place the appropriate number after each statement to indicate the degree to which you used each of the following thoughts/behaviour to deal with your problems.

- 0 = never used
- 1 = rarely used
- 2 = sometimes used
- 3 = regularly used

- 23. Got professional help and did what they recommended
- 24. Changed or grew as a person in a good way
- 25. Went on as if nothing had happened
- 26. Accepted the next best thing to what I wanted
- 27. Talked to someone who could do something about the problem
- 28. Tried to make myself feel better by eating, drinking, smoking, taking medications
- 29. Tried not to act too hastily or follow my own hunch
- 30. Changed something so things would turn out all right
- 31. Avoided being with people in general
- 32. Had fantasies or wishes about how things might turn out
- 33. Just took things one step at a time
- 34. Wished the situation would go away or somehow be finished
- 35. Kept others from knowing how bad things were
- 36. Thought about fantastic or unreal things (like the perfect revenge, or like winning a million pounds) that made me feel better
- 37. Came out of the experience better than when I went in
- 38. Wished that I could change what had happened
- 39. Made a plan of action and followed it
- 40. Talked to someone to find out about the situation
- 41. Tried not to burn my bridges behind me, but left things open somewhat
- 42. Wished I could change the way I felt

**THANK YOU FOR COMPLETING THIS QUESTIONNAIRE**